

Advocating Dignity:
Death with Dignity in the Us, 1985-2011
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ABSTRACT

Advocacy groups work across many aspects of “death with dignity” practice and treatment, and provide insight across multiple aspects of “death with dignity”. This study argues that key advocacy groups in the American death with dignity movement influenced the broader conceptualization of death with dignity in a way that makes patients more able to achieve it. This influence has been a dynamic process across different periods of practice starting the discussion of “death with dignity” in 1985 through today, although this thesis extends only to 2011. The question in this study is how do the three main historical advocacy groups in the US: the Hemlock Society, Compassion in Dying, and Compassion and Choices, conceptualize death with dignity with regards to patient and doctor relationship, legal and policy factors, and medical technologies and protocols? This study found that the Hemlock Society (1980-2005) characterized death with dignity as a terminally ill patient being able to “self-deliver” from suffering via autoeuthanasia regardless of medical community approval or legality. Compassion in Dying (1993-2007) characterized death with dignity as involved advocacy work with terminal patients and their communities to pursue palliative care and hospice up to the point of assisted death. This organization was also involved in the passing of Oregon Death with Dignity Act. Compassion and Choices (2007-present) characterized death with dignity similarly to Compassion in Dying but also advocated for adequate management of pain and suffering symptoms in palliative care to prevent people from desiring death over the illness. Conceptualizing death with dignity is important for understanding why patients want death with dignity and better accommodating their end of life needs when they are suffering with terminal illness.

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TABLE OF CONTENTS

CHAPTER	Page
1 INTRODUCTION.....	1
2 CHAPTER ONE: THE HEMLOCK SOCIETY.....	11
Euthanasia and Religion, 1985.....	15
Final Exit, 1991.....	18
Dying with Dignity, 1992.....	21
Hemlock's Cup, 1993.....	25
Farewell to Hemlock, 2005.....	27
Conclusion.....	28
3 CHAPTER TWO: COMPASSION IN DYING.....	32
Physician and Patient Relationship Factors.....	38
Legal and Policy Factors.....	43
Medical Technology and Protocol Factors.....	47
Conclusion.....	52
4 CHAPTER THREE: COMPASSION AND CHOICES.....	54
Physician and Patient Relationship Factors.....	58
Legal and Policy Factors.....	60
Medical Technology and Protocol Factors	64
Conclusion.....	68
5 CONCLUSIONS.....	71
REFERENCES.....	78
APPENDIX.....	80
A COMPREHENSIVE ORGANIZATIONAL BIBLIOGRAPHY.....	81
B CONCLUSION CHART. FIGURE ONE	84

LIST OF FIGURES

Figure	Page
1. Figure 1: Death with Dignity Conceptualization Conclusions.....	75

Introduction:

This research is an analysis of the conceptualizations of dignity for key advocacy groups central to the death with dignity movement in the US. Historically, dignity has been a vague concept whose definition is variable depending on who's discussing it and even in what context they are discussing it in. This concept cannot be easily defined, but people suffering with terminal illness need a framework for achieving dignity that caregivers and lawmakers can follow too.

Death with dignity as a concept permeates many different areas of society because human illness and suffering is a common experience. Death with dignity principles affect the medical system that treats terminally ill people in terms of how medical caregivers are trained to work with patients, and caregivers recommend and administer treatments in a variety of settings including palliative care and hospice. Death with dignity concepts also shape medical research concerning end of life care and extension of life. Death with dignity treatments affect state and federal courts as states pass death with dignity acts and other laws that redefine end of life care across the US. Disputes over the circumstances of people's deaths bring local courts and lawyers into this sphere as well as grieving families trying to find peace over their loved ones' deaths. Lastly, and most importantly to this research, death with dignity advocacy groups engage people with terminal illnesses and facilitate a wider range of options for care and support. They also lobby for legislative change to allow more death with dignity practices in medical care.

Failures in the American medical system led to the emergence of death with dignity advocacy, concepts, and practices of US death with dignity advocacy groups. Advocacy groups argued that peaceful death at home was almost obsolete for Americans with terminal illness¹. The medical system cast illness as a battleground and patients as warriors fighting for survival. Few thought of the terminally ill as individuals who had affairs to get in order and deserved closure². These unrealistic expectations led to a system lacking dignity and humanity in death.

The following phenomena supported the view of the medical system: the NIH war on cancer in the 70's, the AIDS epidemic of the 80's and 90's, changes in medical care and law to

¹ Cox, D. W. (1993). Hemlock's cup: The struggle for death with dignity. Buffalo, N.Y: Prometheus Books.

² Cox, 1993.

redefine when ending care is acceptable, the Patient Self Determination Act of 1990, the highly public controversy of Dr. Kevorkian, the Terri Schiavo case, and the Palliative Care Information Act (PCIA) of 2011. The PCIA passing also marks the end of the research timeline in this particular study because it was the beginning of the most modern age in death with dignity legislation and treatment changes. Each of these items affected medicine and law in some way that left people wanting more from the end of life experience in America.

By the mid 1970's, cancer was the second leading cause of death in the United States.³ The trajectory of the disease that led to this statistic has been analyzed in many other studies. In the 1970's, the US government became involved formally in the disease and changed the future trajectory of the disease. In 1971 President Nixon signed into action the National Cancer Act of 1971, which created the National Cancer Institute and launched the war on cancer in the US. This act initiated the aggressive cancer treatment research that can be seen in the US today and changed cancer treatment.⁴ With experimental treatments available and this new branding of cancer as an enemy, cancer related deaths seem like an unnatural phenomenon. With the dialogue shifting from disease as a killer to illness as a battle, the incidence of people suffering with prolonged terminal illness increased and the whole concept of death in the medical system changed. Peaceful death at home declined and extreme therapies and highly morbid treatments until the end became the norm.

The early 1980's marked the height of the HIV and AIDS epidemic as well as a paradigm shift in how the medical establishment handled terminally ill people. Unfortunately, lack of understanding of the cause and transmission of HIV and AIDS and the terrible symptoms of the disease led to fear around the treatment of the people with this disease.⁵ Many caregivers feared making contact with AIDS patients and subsequently many patients suffered in horrific conditions

³ "National Cancer Act of 1971." National Cancer Institute, www.cancer.gov/about-nci/legislative/history/national-cancer-act-1971.

⁴ Barker AD, Jordan H. Legislative History of the National Cancer Program. In: Kufe DW, Pollock RE, Weichselbaum RR, et al., editors. Holland-Frei Cancer Medicine. 6th edition. Hamilton (ON): BC Decker; 2003. Available from: <https://www.ncbi-nlm-nih-gov.ezproxy1.lib.asu.edu/books/NBK13873/>

⁵ "A Timeline of HIV and AIDS." HIV.gov, 12 Mar. 2019, www.hiv.gov/hiv-basics/overview/history/hiv-and-aids-timeline.

and alone in their illness. Through media coverage or personal experience, people with the disease and their loved ones and caregivers knew abandonment was a common end-game of the disease. Some people chose to die by their own means to avoid suffering and isolation. The number of suicides and painful deaths that came from the AIDS epidemic in America shone a light on the need for reform in the medical system and other social structures.

Withdrawal of care has multiple meanings. In the case of lucid terminally ill patients, withdrawal of care means either ending curative treatments and shifting comprehensively into palliative care or ending nutrition and hydration in a conscious decision to passively end life. For patients who are not lucid and rely on ventilators for breathing, removing the ventilator is also a form of withdrawal of care. This second meaning is not addressed in this study because the death with dignity movement was concerned with lucid and competent adults who are capable of making their own healthcare decisions. Dying patients who were lucid and who expressed desires to end care were often opposed by their caregivers and loved ones and this led to prolonged suffering and denial of a dying person's wishes for peace. In American medical spheres, "the right of competent patients to refuse unwanted medical treatment, including artificial hydration and nutrition, is [now] a settled ethical and legal issue in this country — based on the right to bodily integrity,"⁶ but this was not the case in all eras studied in this research. The changes in withdrawal of care practices and passive euthanasia will be described in more detail in the individual advocacy era sections.

The federal Patient Self Determination Act (PSDA), written to encourage people to plan for what type of care they want in the case of extreme illness and dying, was passed in 1990. This act was critical to the death with dignity community because it enforced respect for living wills and durable powers of attorney in legal and medical systems across the US. The exact wording of this house resolution is that it

"require[d] hospitals, skilled nursing facilities, home health agencies, hospice programs, and health maintenance organizations to: (1) inform patients of their rights under State law to make decisions concerning their medical care; (2) periodically inquire as to

⁶ Quill, Timothy E. "Terri Schiavo — A Tragedy Compounded." *New England Journal of Medicine*, vol. 352, no. 16, 2005, pp. 1630–1633. *New England Journal of Medicine*, doi:10.1056/nejmp058062.

whether a patient executed an advanced directive and document the patient's wishes regarding their medical care; (3) not discriminate against persons who have executed an advance directive; (4) ensure that legally valid advance directives and documented medical care wishes are implemented to the extent permitted by State law; and (5) provide educational programs for staff, patients, and the community on ethical issues concerning patient self-determination and advance directives.”⁷

This law was also important for the death with dignity movement because it mandated that caregivers inform patients of their rights in healthcare, which facilitated conversations about more options about end of life care.

Jack Kevorkian must be mentioned in any 21st century conversation about death in the United States. In the 1990's, Kevorkian, known as Dr. Death, leveraged his career as a pathologist to create a death machine and to encourage dying people to engage in euthanasia rather than to suffer their illness until natural death. Once connected to this dying machine, an individual could push a button that would administer a lethal dose of medication. This button could be pushed by the individual or by another person, which was legally defined as suicide or euthanasia depending on the person pushing the button. “Mr. Kevorkian says he assisted with more than 130 suicides in the 1990s, when he drew national attention to questions about what rights people have when it comes to dying.”⁸ Kevorkian adamantly stood by his choice to facilitate these deaths even after being convicted and spending eight years in prison. In interview after prison he stated he believed that the Oregon laws did not go far enough in facilitating assisted dying and said that the US was a tyrannical place where euthanasia would never be properly legalized. Many “supporters of assisted suicide have sought to distance themselves from Mr. Kevorkian for his flamboyant, blunt image and for his failure to wait for the laws to change”⁹ and this research study is also distant from all death with dignity work of Kevorkian and all sentiments of Kevorkian’s methods.

The Terri Schiavo case created a discourse on how to determine what a patient would have wanted when there is no way to ask them anymore and it also created awareness for living

⁷ Levin, Sander M. “H.R.4449 - 101st Congress (1989-1990): Patient Self Determination Act of 1990.” Congress.gov, Library of Congress, 2 July 1990, www.congress.gov/bill/101st-congress/house-bill/4449.

⁸ Davey, Monica. “Kevorkian Speaks After His Release From Prison.” The New York Times, The New York Times, 4 June 2007, www.nytimes.com/2007/06/04/us/04kevorkian.html.

⁹ See Footnote 6

wills, do not resuscitate orders, and advanced directives in the case of a persistent vegetative state. Terri Schiavo was an otherwise healthy woman who lapsed into a vegetative state in 1990 for reasons that are still undetermined. After doctors determined she would permanently remain in the vegetative state, Schiavo's husband requested to withdraw her life sustaining care to let her die naturally, but Schiavo's parents argued vehemently that Schiavo was still alive and must receive care. This led to a heated and prolonged legal battle that rose through the courts in Florida up to the federal level and even crossed the executive desk.¹⁰ The main legal issue to be addressed in this case was what would Schiavo's personal wishes have been in this case and who should be responsible for enacting her substituted judgment. Ultimately, Schiavo was removed from life support in 2005 and passed a few days after. This case created a precedent for substituted judgment in terminal cases because "the evidence [was] clear [for brain death], as the courts found in the case of Terri Schiavo, then enforcing life-prolonging treatment against what is agreed to be the patient's will is both unethical and illegal."¹¹ This precedent taught that the courts are not an ideal place to settle disputes over medical care at the end of life-- it is far better to have a plan in place and a discussion ahead of these circumstances. This case also created an awareness on the part of the medical and bioethics communities that ideas with death and dying need to be realigned to understand that it is a natural part of life and not something that can be avoided.

After the case of Terri Schiavo and multiple other public cases of lucid patients receiving mixed messages about ideal care at the end of life, New York state passed the Palliative Care Information Act (PCIA) of 2011. This was a groundbreaking law that enforced communication in the medical system of full end of life treatment. New York's legislation created an example of more progressive death with dignity communication legislation and a model for other states. This law mandated that medical caregivers communicate honest prognoses to patients and it required

¹⁰ Quill, Timothy E. "Terri Schiavo — A Tragedy Compounded." *New England Journal of Medicine*, vol. 352, no. 16, 2005, pp. 1630–1633. *New England Journal of Medicine*, doi:10.1056/nejmp058062.

¹¹ Quill, T. E. See footnote 8

caregivers to inform terminally ill people about palliative care, hospice, and end-of-life options.¹²

The law also required caregivers to communicate to patients their legal rights to full pain and symptom management and the risks and benefits of different palliative treatment options. This law is unique because it was the first to require that patients be given information about non-curative treatments when they are known to be dying. The previous norm in healthcare was to give doctors the jurisdiction on whether they would communicate palliative care options and this situation was problematic because it caused many people to think that their only recourse was pursuing curative treatments until the end and/or suffering with extraordinary pain.

This project is situated within that rich history of patient agency and medical responsibility surrounding end of life care from the mid 1980's onward, and maps the understanding of dignity in death thorough examination of three major organizations: the Hemlock Society, Compassion in Dying (sometimes referred to as the Compassion in Dying Federation), and Compassion and Choices. Many different religious, medical, social, and legal groups in the US have advocated for death with dignity, along with many smaller organizations that have aided patients in this field and have influenced the field in different ways. This study examines the Hemlock Society, Compassion in Dying, and Compassion and Choices because of the large number of patients they impacted and the multiple spheres they influenced in their death with dignity work. These three large groups had the most significant impact on the development of the concept of death with dignity, patient advocacy at end of life, and choice in dying.

Advocacy groups have direct advice on how to act in ways that people communicate with and interact with their doctors and larger care teams, advice on how to maneuver through laws that both restrict and facilitate death with dignity treatments, and advice on what the current options are for terminal treatment in medical technologies and medical protocols. To capture the changing concept of death with dignity, this research will examine those three major dimensions of thought by engaging with each advocacy group's published literature.

¹² "Department of Health." Palliative Care Information Act, New York State , 9 Feb. 2011, www.health.ny.gov/professionals/patients/patient_rights/palliative_care/information_act.htm.

In doing so, this thesis examines the question: How do the Hemlock Society, Compassion in Dying, and Compassion and Choices' conceptualizations of death with dignity change over time with respect to the variables of patient and doctor relationships, legal and policy factors, and medical technologies and protocols?

To answer that question, this thesis examines publications from those three advocacy groups surrounding the changing conceptualizations of dignity with respect to 1. patient and doctor relationships, 2. legal and policy factors, and 3. medical technologies and protocols.

To do this, this thesis will be structured with each of the Hemlock Society, Compassion in Dying, and Compassion and Choices analyzed based on their primary sources of advocacy literature in chronological order of when the organizations existed. The Hemlock Society's chapter is structured by the different periods (early, middle, and late) based on the publication of literature and the style of advocacy recommended by the society. This structure is intended to best capture the evolution of advocacy for the first group present in the US from an emergent era of unprecedented advocacy work up to an established organization with external influence from society and other spheres. Compassion in Dying's chapter is structured with the three variables of patient and doctor relationship, legal and policy factors, and medical technologies and protocols analyzed separately with regards to the full literature selection for Compassion in Dying in order of publication. This structure is meant to organize the conceptualizations of death with dignity from this society in a way that emphasizes its overall advocacy impact in those variable areas instead of commenting on the repetition of publication over time for this group. Compassion and Choices is structured in the same way that Compassion in Dying is but without chronological order of the organizations' publications in each of the variable sections. Compassion and Choices holds many similarities to Compassion in Dying, and the similar structure of their chapters reflects this and highlights the differences between the organizations over time.

The Hemlock Society publications began with the 1985 publication of Gerald A. Larue's, *Euthanasia and Religion*, the first publication that formally mentioned the Hemlock Society as an organization. The Hemlock Society was the first death with dignity advocacy group that formally existed in America and was founded partially in response to the mortality rates of the AIDS

epidemic.¹³ This group was founded by a Derek Humphry and Gerald A. Larue among others and advocated for patients only through published literature and newsletters. This group recommended that terminally ill people engage in more dignified deaths by pursuing “self-deliverance” or physician-assisted suicide to end their suffering on their own terms. They wrote that self-deliverance could be achieved without the help of the medical system and illegally if doctors and laws did not support the will of the patient. This group was highly controversial but was critical to the death with dignity movement because it disrupted the medical and legal status quo around terminal illness in the late 20th century and paved the way for future death with dignity advocacy groups to initiate dramatic change in the field. The selection of literature that was chosen to represent the views and work of the Hemlock Society is as follows: *Euthanasia and Religion* (1985), *Final Exit* (1991), *Dying with Dignity* (1992), *Hemlock’s Cup* (1993), and “Farewell to Hemlock” (2005). These pieces cover the whole period of the Hemlock Society’s existence and they were published at intervals in the society’s existence that mark different periods of legal and medical potential and offer the most complete examination of the Hemlock Society’s views on death with dignity.

Compassion in Dying existed at the same time as the Hemlock Society from its founding in 1993 to the Hemlock Society’s end in 2005. Compassion in Dying’s advocacy was both hands on and distributed through published work. This group is probably most well known for their role in the legalization of the Oregon Death with Dignity Act and their concerted efforts to legalize physician aided dying around the US. This group also strongly advocated that terminally ill people pursue hospice and palliative care to relieve their suffering and pain at the end of life rather than pursue curative treatments in a clinical and sterile environment. The publications selected for Compassion in Dying were *Physician Assisted Dying* (2003), *Caring for the Dying: Critical Issues at the Edge of Life* (2003), and *Euthanasia* (2005).

Compassion and Choices is the final advocacy group examined in this study and was founded in 2007 when Compassion in Dying was ended and rebranded to be Compassion and

¹³ Humphry, D. (1992). *Dying with dignity: Understanding euthanasia*. Secaucus, N.J: Carol Pub. Group.

Choices. This group has many similarities to Compassion in Dying but, in addition, they advocate strongly for adequate pain management for terminally ill people in all circumstances. Compassion and Choices is responsible for several more death with dignity acts passing in the US and articulates that physician aided dying should only be pursued when it is legal and medically sound. This group is still active and ushered the death with dignity movement into a modern era as well as mitigated concerns about the ethics of end of life treatments around the country. The publications for Compassion and Choices were “End-of-life Bill Empowers Sick Patients” (2008), “Last Rights” (2009), “The Palliative Care Information Act” (2011), “The Crime of Assisting a Suicide” (2011), “Life, Liberty, and the Right to Die” (2013), “Aid in Dying is Different from Assisted Suicide” (2014), “Prolonging life: Legal, ethical, and social dilemmas” (2014), and the Compassion and Choices website (compassionandchoices.org).

Together, these three organizations changed the death with dignity field in the US from the late twentieth century to present day. As mentioned above, there were a series of events in the late twentieth century that shaped the dying process in the US to be something that was lacking in autonomy, peace, and choice. There was notice of this phenomenon by the founders of the Hemlock Society and their earlier followers. Through the joint efforts of these groups, death with dignity practices went from being very vague and limited to including self-deliverance at home and outside of the medical system, to including legislation allowing for physician aided dying in Oregon and later in other states, to including at home support care through hospice and palliation funding and awareness, and up to present day with insistence on open communication of all treatment options including support healing and curative healing. Aid in dying is one small piece of modern death with dignity practices and technologies and is preceded by pain management technologies and suffering relief treatments. Modern death with dignity involves the community of the patient and facilitating choices at the end of life for patients that return to them their sense of self and autonomy. The following three chapters will examine the nuanced changes in the death with dignity movement in the US from 1985-2011 that lead to the dramatic strides in the field from its emergence to its present state.

Chapter One

The Hemlock Society: The Dawn of Death with Dignity Advocacy in the US

The Hemlock Society was the first major organization in the United States to provide any version of a centralized platform for terminally ill persons to seek out advice and treatment guidance outside of their direct care provider. This organization arose at a time when there was no external guidance for patients in hospital care and even when hospice and palliative care were not widely available for the dying. When analyzing the advocacy that Hemlock Society provided it is important to consider that there was not an American precedent for death with dignity advocacy.

The Hemlock Society shaped the early death with dignity concepts and advocacy in the US. The books and publications analyzed in this chapter are selected based on their candid presentation of the views of Hemlock Society and for how they acted as an influence in terminally ill people's lives and the work of their caregivers. The Hemlock Society relied heavily on publications to disseminate information to its followers rather than individualized contact with its followers, which means that the publications analyzed represent the full range of advocacy for the group. The books selected each represent a different facet of the society's evolution in stature and views and are divided between early, middle, and late stages of the Hemlock Society. Each of these eras will be separately analyzed on each of the three factor levels in the question that are used to conceptualize dignity and death with dignity practices in advocacy. Again, these factor levels are patient and doctor relationship, legal and policy factors, and medical technologies and protocols.

Death with dignity (DWD) advocacy in the United States has changed dramatically since the early 1980's. At the beginning of that decade, there were no centralized advocacy groups in the US for DWD. The lack of advocacy groups did not correlate with the number of terminally ill patients suffering in their illnesses and seeking alternative options for their dying processes. The need for advocacy groups in terminal illness became more obvious when the AIDS epidemic broke out in the US and people were left desperate and alone on their deathbeds with limited information about a disease that had impacted their quality of life and dignity. Many of these

people were abandoned by their caregivers for fear of the contagiousness of the disease and took their lives to escape the acute physical and emotional suffering of the disease. This sets the scene for the emergence of the Hemlock Society and the DWD movement.

Derek Humphry and Gerald Larue founded the Hemlock Society in 1980.¹⁴ These two individuals had very different professional training and backgrounds, but similar life experiences led them to create the first advocacy group aiding patients in a dignified death in the US. Hemlock Society disseminated literature that educated terminally ill people on how to exercise personal agency at the end of life and how to end their lives voluntarily, free of violence, and on their own terms, if that was their goal.

Both Humphry and Larue experienced end of life tragedies at close range and decided that terminally ill people needed greater variety in ways to end life. Larue was a professor of religion and an adjunct professor of gerontology at the University of Southern California, and he worked as a family and marriage therapist in Beverly Hills. Larue's therapy practice particularly focused on death, grief, loss, and attempted suicide.¹⁵ Through his therapy practice and research, Larue experienced the emotional and more tangible needs of people coping with illness and death. He saw loneliness, suffering, and dissatisfaction with the options available at the end of life. Derek Humphry was a journalist living and working in the UK in the early 70's when his wife, Jean, suffered from aggressive breast cancer. In 1975, at Jean's request, Humphry helped end her life and suffering with an overdose of prescription barbiturates in a cup of coffee, which Jean drank of her own accord. Humphry chronicled this experience in detail in a book titled *Jean's Way* that was widely published and distributed in the UK and US and later in much of the western world. After publication, Humphry faced serious professional and personal backlash from those who disagreed with his choice to aid in his wife's death rather than let her die of her disease through natural causes. Humphry narrowly avoided going to trial in the UK after being charged

¹⁴ Humphry, D. (1992). *Dying with dignity: Understanding euthanasia*. Secaucus, N.J: Carol Pub. Group.

¹⁵ Larue, G. A. (1985). *Euthanasia and Religion*. Los Angeles, CA: The Hemlock Society.

Torr, J. D. (2000). *Euthanasia: Opposing viewpoints*. San Diego: Greenhaven Press. [pg vii]

with accessory to murder of his wife and relocated to Los Angeles to escape the fallout from his book publication.

Humphry and Larue founded the Hemlock Society on August 12, 1980 in Santa Monica, California to help terminally ill individuals find “self-deliverance,” which is a term the society created for terminally ill people choosing when and how to die. After meeting and discussing these experiences, they agreed that something could be done to help people have better dying experiences. People should not be left without options at the end of life in cases of terminal illness. Explaining the origins of the organization, Humphry stated “no organization in America was tackling the issue of voluntary euthanasia for the terminally ill through assisted suicide. There were many such groups in other countries.”¹⁶ Further he articulated the Hemlock Society’s mission as:

“[The Hemlock Society] supports the principle of a person who is terminally ill and suffering to choose to end his/her life, and if necessary get help doing so, ideally from a physician. This is not yet lawful. Through books, newsletters, pamphlets, talks, the media, conferences, and its chapters, the matter is discussed.”¹⁷

This mission statement and the foundations of the Hemlock Society shaped the organization’s involvement in its members’ lives and, most importantly, its influence and advocacy work with terminally ill and dying patients during its years of active operation. This advocacy group projected its message loudly in the media and garnered attention through ample publications. The Hemlock Society offered the first platform for people to have a community to ask questions about how to die with dignity and to receive a variety of information in return. The Hemlock Society chose not to give personal counseling and advice because it caused liability; however, the First Amendment (Freedom of Speech) protected the writings and publications of the group from legal retaliation. Members of the group relied on the publications of the society for pertinent information on how to cope with terminal illness and pursue self-deliverance. The individual chapters of the society sometimes facilitated group sessions for peer support in difficult situations surrounding death with dignity. The group advised that individuals pursuing self-

¹⁶ Humphry, D. (1992). *Dying with dignity: Understanding euthanasia*. Secaucus, N.J: Carol Pub. Group. [pg 175, ch 19]

¹⁷ Humphry, Dying with dignity. P.176

deliverance do so with the aid of their own physicians—not with physicians connected to the group. Within these parameters, the Hemlock Society mainly worked in patient education in understanding types of death available and in empowering patients to request access to their preferred dying methods. Hemlock Society did not work much to change policy to make different types of death with dignity legal. Instead, it educated patients on how to achieve self-deliverance from terminal illness in ways that circumvented the law and the restraints of the medical system. The organization was important during this era in influencing the lives and deaths of those who sought solace from suffering terminal illness during the end stages of life.

The key pieces of literature that directors of the Hemlock Society published during its active years are analyzed chronologically in the remainder of this chapter with respect to the ways in which they conceptualize a dignified death. The recommendations for how to achieve a dignified death published by the Hemlock Society all must do with identifying when the patient is ready to die and then taking nonviolent and community-oriented measures to end the patient's life before the disease does. The recommendations for how to end a life physically change very little, but the social and medical circumstances of these conceptualizations do change over time. The key areas of how a dignified death is conceptualized by this group are analyzed in: 1. the context of the patient and physician interactions, 2. in law and policy, 3. and in medical protocol and technology.

The Hemlock Society created a platform to discuss the controversial topic of death with dignity, through its loud and public work to advocate that terminally ill patients' needs be prioritized above all else in this area of medicine, and because their opinions caused the emergence of social and political change in the arenas surrounding DWD. I will go through their conceptualizations to show the changes from early voice of patient control and autonomy, to middle stages of recommending radical protocol and technologies for self-deliverance, to late stage awareness of the complexities of pursuing a dignified death in the legal and medical communities. These changes are chronicled in key publications from the society below in order of when they were documented and shared with the public.

Early Hemlock Society: *Euthanasia and Religion*, 1985

In the early stage of the Hemlock Society, there was limited practice surrounding palliative care and hospice, and this led to limited awareness for the full range of treatments that are now associated with DWD. This was also during the AIDS epidemic where suicide was too common for terminal illness and the Hemlock Society was still engaged in analyzing where improvements could be made to minimize this. *Euthanasia and Religion* was one of the original texts published by a Hemlock Society director, who was also a therapist and religious professor, after its official founding as an organization. Larue's introduction to this book explains the Hemlock Society's position in society at that time and its views. This book is the publication of a stratified study that Larue conducted through Hemlock Society to document the different religious and spiritual views of DWD across the United States. In this period, individuals faced both legal and medical barriers to passive and active euthanasia. Passive euthanasia is characterized by withdrawal of treatments that keep the patient alive and active euthanasia is characterized as taking a medication or other measures to end life at specific time determined by the patient. Hemlock Society advocated for both euthanasia types as options for self-deliverance and disseminated information on both.

In this book, the Hemlock society's conceptualizations of Death with Dignity were vague in regards to technological intervention but clear in doctor patient relationship and legal terms. In 1985, Hemlock Society leaders thought physicians who were asked to aid a patient in dying should put aside their own qualms and aid the patient in achieving his or her goals to the best of that physician's ability. The society understood that this was not always possible but asserted that the patients' needs ought to come before the physicians' in the case of terminal illness and self-determination. Physician-assisted suicide was not legal at this time so the group advised that dying individuals circumvent the law to achieve death with dignity. Organization leaders believed that if a physician would not help pharmaceutically, dying individuals had the right to use whatever method available to them for self-deliverance.

In 1985 physician-assisted suicide was not legal and considered active euthanasia¹⁸. The definition that Larue gave for active euthanasia is “the deliberate intervention into the life process by the patient who is terminally ill and in intractable pain, or by the patient acting with the assistance of some other person, or by some person acting on behalf of the patient”¹⁹ in which the intervention ends in the patient’s death per the patient’s wishes. Larue strongly argued that consent matters in the doctor-patient relationship in these circumstances and that the only correct context for active euthanasia is when it is fully adhering to the patient’s communicated wishes.

Passive euthanasia was a large platform issue in 1985 for the Hemlock Society because it was more legal than active euthanasia, but it was still controversial. The definition that Larue gave of passive euthanasia was “the removal of life-support systems or the cessation of what have been called ‘heroic measures’ to continue life when the patient is in intractable pain with terminal illness, or is in irreversible coma, and when the removal of the support system will result in the death of the patient.”²⁰ The life-support systems included ventilators, feeding tubes, and curative treatments for the patient’s specific disease. Inevitable death is the only tolerable context for a patient. Larue documents that doctors were wary of aiding in passive euthanasia²¹ because they had mixed views on the ethics and morality of whether or not this was killing a patient and because they feared legal recourse for hastening patients’ deaths. Larue asserted that medical views on using heroic treatments, or curative efforts for a prognosis that is already fatal, on terminally ill patients was not in the patient’s best interest. Larue also depicts a Hemlock view of doctors’ role in the patient’s healthcare when he quotes America surgeon Alfred Jaretzki: “The physician not only has the moral and legal authority to allow his terminal patient to die in dignity, but in my opinion, has the clear obligation to do so as well.”²²

¹⁸ “During this time, Kevorkian was working in Michigan to facilitate suicide for ill people via his death machine. This was physician-assisted suicide and was not legal, and it also does not align with any future version of physician aided dying both legal and illegal.” (Davey, 2007)

¹⁹ Larue, G. A. (1985). *Euthanasia and Religion*. Los Angeles, CA: The Hemlock Society.

Torr, J. D. (2000). *Euthanasia: Opposing viewpoints*. San Diego: Greenhaven Press. Page 145

²⁰ Larue, 1985. Page 145

²¹ Larue, 1985. Pages 10-11

²² Larue, 1985. Page 15

The society asserted that physicians should prioritize a patient's need to die with dignity even in cases of weariness such as with passive euthanasia and its legal grey zones. Larue also insinuated in this same area of opinion that doctors' desires to heal patients are trumped by patients' desires to die with dignity. Furthermore, the society said that in these cases where death is inevitable, the battle against the disease has already been lost. Why force a professional view of health and healing upon the dying patient who cannot benefit from healing efforts? "When the actual confrontation with painful terminal illness is involved, quite often the reasoned theologian and ethical responses become secondary"²³ in hierarchy of importance for the patient. Larue took this one step further by arguing that most physicians "conveniently ignore the plight of a terminally ill patient in intractable pain who requests help in dying from the physician or from anyone who cares about the patient's feelings."²⁴ This was an example of the unideal state of physician and patient interaction by the Hemlock Society.

The society stated that due to the grey zones on when passive euthanasia was tolerable and not legally punishable, many doctors were reluctant to give their patients prognoses. It became risky professional and legal behavior to communicate to a patient how long you believed they had left to live because it could put the doctor and other caregivers in the uncomfortable position of being torn between meeting the patients' requests for a hastened death and their own needs to be removed from a passive/active euthanasia scenario. The Hemlock Society respected that this was a difficult situation for doctors to be in, but still repeatedly argued that doctors' qualms should be secondary to the patients' needs and requests.

Larue described this as the crucial situation for the patient. At the stage where the patient's illness is crucial and death is imminent, the society wants patients to know that "some doctors take matters into their own hands"²⁵ in that they have pity on the patient and communicate the full (including illegal) range of options that the patient has for their treatment at the end of life and to hasten death. Larue also pointed out the other end of the caregiver spectrum in which doctors decided to have minimal involvement in the patient's plan for end of

²³ Larue, 1985. Page 18

²⁴ Larue, 1985. Page 15

²⁵ Larue, 195. Page 18

life. In these cases, the society recommended that the patient find a new doctor who was more willing to aid the patient in the full range of needs at the end of life.

The issues around passive and active euthanasia that the society depicted in this stage were not all of confusion and stress though. Larue pointed out that the emergence of the first medical course to teach future doctors about psychological aspects of life-threatening illness at Vanderbilt Medical School was a promising step forward in creating greater empathy in the medical field for terminally ill patients. He believed that at the time, “Most medical personnel and psychotherapists have little or no familiarity with the ways in which the different religions of the world confront death”²⁶ and that this also diminishes the ways in which doctors prioritize empathy for patients when choosing how much of a role to play in a patient’s death and end of life.

Larue did not discuss the state of DWD medical technology and protocols in this book. However, it can be clearly seen by the discrepancies between patients’ DWD requests and doctors’ desires to be excluded from those requests listed in the sections above that there was not much infrastructure for self-deliverance in the medical system in a legal way. At this time, passive euthanasia was legal, so one protocol that patients had was to choose to stop eating and drinking water if they were terminally ill. This required much communication with their doctors, care team, and family to ensure that everyone around the patient would support their choice to die in this way (passive euthanasia) and that they would not intervene to provide the patient involuntary nutrition and hydration. It often took several days to a week for a person to die in this manner. Pain management also existed as a protocol, but pain medications at this time were not utilized in a way that was substantially effective.

Middle Stage Hemlock Society: *Final exit: The practicalities of self-deliverance and assisted suicide for the dying, 1991*

In 1991, physician-assisted suicide was still illegal in every state in the US and the Hemlock Society acknowledged this. This acknowledgment was coupled with the Hemlock Society advising patients to carefully work outside of the bounds of the law to achieve their goals

²⁶ Larue, 1985. Page 12

for self-deliverance. *Final Exit* was the Hemlock Society's advice to its members on how to achieve death on their own terms in ways that are humane and circumvent reliance on the medical profession and the law. The society argued that people who are ill deserve the opportunity for humane self-deliverance with whatever means they have available to them. The medical technology that the society recommended for autonomous self-determination are the main characterization of the mid-life of the Hemlock Society.

Final Exit was one of the most famous and controversial books that the Hemlock Society published and was the main method for the Hemlock Society's information about medical protocol and technology for end of life treatment to achieve DWD. *Final Exit* was controversial because it contained a detailed set of options on how to take a human life as nonviolently and dignified as possible in the event that self deliverance is desired or necessary in terminal illness. This book gave detailed information on how to procure the items needed for each documented way to die and how to use those items. A sampling of the options for self-deliverance in *Final Exit* include asphyxiation with a plastic bag, use of carbon monoxide from a car, and a table of different over-the-counter medications and chemicals that can be combined to cause death and what quantities to combine those in for individual patient weights and conditions.

Again, active euthanasia was not legal when this was written and passive euthanasia was only legal in some capacities depending on whether or not terminally ill people's caregivers agreed with their choices to withdraw care or hasten death. The Hemlock Society was directly advocating that patients who wish to hasten their death take this process into their own hands with the methods described in this book and engage in active euthanasia. The Hemlock Society was fully aware that this was not legal and advocated for patients to work outside of the legal system. Many critics of this book and the society's teachings believe that the Hemlock Society's resources could have been used to advocate for legalization of physician-aided dying rather than teaching people how to end their lives without regulation and management of the medical system and illegally.

It's important to note that this book was also highly controversial because it gave detailed information on how an individual could successfully terminate their life and provided a single page at the beginning of the book cautioning readers to use the information only in the event of terminal illness. The Hemlock Society had the best intentions for its members when it published *Final Exit*, but they also had a very large platform that this book reached and many believe that not enough was done by the society to urge mentally ill and depressed individuals considering suicide to not use the methods in the book. The widespread controversy surrounding this book was also indicative of how largely it was read and distributed. When the *New York Times* wrote how the book had shot to the top of its best seller list, it also wrote "that [the book] is an indication of how large the issue of euthanasia looms in our society now," said Dr. Arthur Caplan, a bioethicist at the University of Minnesota in Minneapolis. 'It is frightening and disturbing and that kind of sales figure is a shot across the bow. It is the loudest statement of protest of how medicine is dealing with terminal illness and dying.'²⁷ Again, the Hemlock Society had a very large platform at this stage and that large platform all had access to this book along with any other readers of the *New York Times* bestseller list. This platform was being used to encourage people to take their health and death into their own hands in the cases that life with terminal illness was intolerable.

A more complete list of the options that *Final Exit* suggested to people for self-deliverance included information on hospice, death with cyanide, death by starvation, obtaining barbiturate doses from doctors, death by carbon monoxide, self-deliverance by asphyxiation with a plastic bag, inhalation of inert gasses, along with a table of drugs and exactly what doses and processes to use them with to end life. Humphry's other chapters in this book included warnings on avoiding illegal activity that would implicate loved ones and caregivers in these processes, pleas that the dying individual leave notes behind delineating why they wanted to die, recommendations for how to talk to your community about your decision, information on life

²⁷ Altman, Lawrence K. "How-to Book on Suicide Is Atop Best Seller List ." *New York Times* , 9 Aug. 1991, p. A00010 , www.nytimes.com/1991/08/09/us/how-to-book-on-suicide-is-atop-best-seller-list.html.

insurance and legal processes following your death, choosing when to die, and a checklist of questions to ask to decide if self-deliverance is truly the best option in your case.

Middle Stage Hemlock Society: Dying with Dignity: Understanding Euthanasia, 1992

In 1992, the Hemlock Society began to address the need for policy reform to protect those who aid their loved ones in self-deliverance and to protect doctors who comply with their patients' requests for self-deliverance. This showed a shift from previous Hemlock Society stances that self-deliverance involves necessitates a burden on the patient to work outside of the law to the burden being on policy makers to update the law. The technology in this era was recommended in the same way that it was previously, meaning that a patient should seek out their doctor's aid if possible for self-deliverance and use whatever means were available to them if this is not possible.

In *Dying with Dignity: Understanding Euthanasia*, Derek Humphry gave an updated count of the Hemlock Society's opinions on DWD and he reinforced that patients ought to confer with their doctors for help on how to achieve a hastened death when they desired it. He gives more information in this book about the doctor's role in this process. He acknowledged the tricky situation requires of the medical profession in given that physician-assisted suicide is not legal and given that the bounds of assisting death by means of removing lifesaving technology is both painful and has potential recourse. At this stage in advocacy, the Hemlock Society also began to add commentary on the state of policy and legality of different DWD practices rather than simply stating that the law does not cooperate with patient needs and ought to be circumvented.

Derek Humphry had many points on how the doctor patient relationship ought to work in cases of terminal illness. In this stage of the Hemlock Society, Humphry still advised terminally ill patients to ask their doctors for lethal dosages of medication despite the illegality of this practice. Humphry noted that doctors frequently agreed to do so for dying AIDS patients during the AIDS epidemic and proposed that the same approach should be used with other modern

terminal illnesses. The Hemlock Society firmly preached that autoeuthanasia, or self-deliverance from illness and suffering, should be nonviolent, painless, and bloodless as factors of the dignity that comes with this type of death. These phenomena were easiest to achieve when a doctor aids the process with a prescription to end life. This view was interestingly contradicted when Humphry followed it saying, "Don't trust a doctor to tell you how to end your life! Most don't know how."²⁸ This meant that patients needed to ask for help from physicians in securing autoeuthanasia but that the patients needed to refer to the Hemlock Society for how to secure a safe and swift death because Humphry thought that doctors were not trained in how to efficiently end a life. And this was partially true at the time because most medical schools did not teach how to end a life and clinical practice did not teach it either.

The Hemlock Society believed that physicians should be supportive of patients seeking voluntary euthanasia in terminal illness and also expressed that physicians who saw this as harming a patient and breaking the Hippocratic oath are part of a medical establishment that "has let the people down by keeping its eyes fixed on the ethics of Greece of 2000 years ago."²⁹ Just as in previous writings, the Hemlock Society was implying the needs of the terminally ill patients that doctors treat to die in a dignified manner supersede the moral and ethical dilemmas doctors struggle with over these requests. The needs of these patients were critical and supreme in the eyes of the Hemlock Society and they encouraged their followers and members to take control of their own dying processes if they wanted to die with dignity. This was evident in Humphry's quote that, "Self- deliverance is the terminally ill individual electing a hastened death to avoid additional suffering. If a person cannot control this crucial phase of existence, what real freedom is there in this life?"³⁰ To the Hemlock Society, there is no real freedom as a human if one can't have dignity throughout all stages of life including death.

²⁸ Humphry, D. (1992). Dying with dignity: Understanding euthanasia. Secaucus, N.J: Carol Pub. Group. Page 140

²⁹ Humphry, 1992. Page 64

³⁰ Humphry, 1992. Page 106

This book marks an emergence of viewpoints and conceptualizations of how DWD is affected by law and policy. The early Hemlock discussion implied that just because something was illegal did not mean that it was not occurring-- it meant that it was occurring in an unregulated fashion that subjected it to more abuse and harm than if it were legal. This was a wise initial stance for the Hemlock Society during their shift into policy concern for DWD because it was a true sentiment that has been echoed in many other modern and retro issues of human existence and government control such as in prohibition and marijuana use. Humphry claimed that, "Now is the time to bring this practice under lawful regulation and public scrutiny."³¹ Even while the society advocated for the public to address their government and ask for better laws to regulate DWD, they argued that patients needed to seize control over their own deaths regardless of the law. A very clear pathos argument was being made on behalf of the dying when Humphry stated that, "some people cannot wait for the laws to be changed"³² because they were too sick and would die waiting. These individuals should not have been forced to experience the natural death that was in store for them because of the views of legislators and members of the public who were not experiencing the reality that those individuals were. This pathos argument was extended one more step when Humphry claimed that, "Our legislators have failed" because they were allegedly intimidated by the right to die movement and because they still punished those who tried to aid patients in their DWD requests. The punitive reactions of courts in DWD scenarios made it even more difficult to access a controlled and dignified exit from terminal illness symptoms. Lobbying to pass death with dignity acts did exist in the society at this time in certain states, but the efforts were not centralized nor collaborative and focused on the individual states where each chapter was operating.³³

The specific demand of the Hemlock Society was that both active and passive euthanasia be legalized and regulated in all 50 states. The Hemlock Society used initiative 119 in Washington as an example of how this could be achieved. This initiative was a very early draft of

³¹ Humphry, 1992. Page 45

³² Humphry, 1992. Page 60

³³ Humphry, 1992. Last Chapter

a potential DWD act that was rejected but had a “request for help dying” that seemed like a good piece of legislation to the society. In the case for passive euthanasia, at this time, the American Medical Association recognized artificial feeding mechanisms could be removed from hopelessly comatose patients as a welcome (and potentially tardy) acceptance of their inevitable death³⁴.

Another new legal and policy conversation emerged in the Hemlock Society at this time that aided in conceptualizing dignity at the end of life. The Hemlock Society included information in this book on what living wills were and how to properly use them. At this time, 40 states had legalized living wills as a respected legal document and 44 states had some version of legislation governing living will usage. This marked a new option for self-possession in the dying process for ill patients, but only in the cases where patients are no longer able to make their own medical decisions due to coma and lack of lucidness. This was still not inclusive to the whole population of terminally ill patients with needs for dignity at the end of life because DWD focuses on people who are lucid and making their own decisions. Nevertheless, the advice on living wills was helpful and progressive information for the Hemlock Society to share with their followers. The society advised followers to also use a durable power of attorney in addition to living wills because a living will was a request for medical caregivers to comply with wishes whereas a power of attorney was more of a demand for compliance.

There were some small but significant shifts in medical protocol and technology that the society urged its members to be aware of at this time. Humphry educated readers that as of 1986, 38 states have adopted the definition of brain death as being compatible with end of life and that the 1981 Uniform Determination of Death Act defines death as the following: Irreversible cessation of respiratory and circulatory functions or Irreversible cessation of all brain function including the brain stem.³⁵ This was valuable for the loved ones of dying patients to know because the emergence of more sophisticated PET scans made it easier to determine when

³⁴ Humphry, 1992. Pages 89-90

³⁵ Humphry, 1992

death had occurred and facilitated the withdrawal of treatment for people who had expressed that they do not want to be kept alive via extraordinary measures. This was an advance in the society's conceptualizations of DWD and the intentional communication of this information was likely fueled by the public drama around the Terri Schiavo case.

Middle Stage Hemlock: Hemlock's Cup: The Struggle for Death with Dignity, 1993

The early 1990's were a dynamic era for the Hemlock Society. In 1993, physician assisted suicide (as it was still called at this time) was illegal in every state in the US and the Hemlock Society began acknowledging that there was unfair risk and harm to doctors who were aiding patients in their desired deaths. This showed a stark contrast to previous sentiments that it was the role of the doctor to help an ailing patient despite the moral qualms of and risk to said doctor. This is was still a patient-centric approach to DWD but the historical context that the society garnered with 10 years in operation influenced new views on physician role in conceptualizing DWD.

Hemlock's Cup was a historical account of the DWD movement to date in 1993 by Donald W. Cox, a physician who was an outspoken proponent of the movement. The chapters of the book that pertain to the Hemlock Society and are reviewed in this research are 1,2,3, and 4, or "Part I: The Door Reopens." Cox iterates the society was acknowledging at this time that physicians who acted to assist patients to hasten their deaths could be prosecuted in all states in the US. They risked being fined, incarcerated, and losing their licenses. This created contention in the public and in the society over what a doctor's role ought to be in a dying patient's care. Was he or she meant to give the patient as much time alive as medically possible or was he or she meant to facilitate the patient's wishes and comfort-- even at the risk of the patient's death?

People who sought euthanasia could be people who had gone to doctors and who knew that when you become a patient, often you cease to be an actor and become acted upon³⁶. This view was exacerbated by the commentary that the medical community harmed people by

³⁶ Cox, D. W. (1993). *Hemlock's cup: The struggle for death with dignity*. Buffalo, N.Y: Prometheus Books.
Page 60

overusing medical technology to prolong life. Cure-oriented models of care may not be beneficial to all patients in this stage of life. These technologies and relationship dynamics can lead a patient to feel even less in control of their life even in the company of someone who is meant to be helping the patient. Furthermore, Cox shared the following quote from Humphry on this issue: "There is a deep-seated fear of high-tech medicine in America, of being locked into machines and losing control of their own lives... Let's make no mistake. Something is going on, whether you like it or not, with a growing segment of the American populace wanting the right to end their own lives if they are terminally ill or injured."³⁷ Advances in medical technology had left many more afraid of dying than of death at this time according to the society. Some terminally ill people knew from experience that certain illnesses leave the sick stripped of everything they think makes life worth living, prisoners of pain and indignity. Fears associated with current modern medical technology associated with terminal illness that Cox cited as being important to terminally ill patients were: being kept alive by I.V. feeding tubes in a nursing home, being subjected to life-prolonging drugs with high morbidities, legal court battles of family members over prolonging the life of a terminally ill and incapacitated family member, the dread of losing control over quality of life and poor treatment by inadequately trained medical staff, and fear of having health insurance canceled at any time. These were all medical protocol factors that detracted from a dignified death and that the Hemlock Society was advocating for terminally ill patients to avoid.

Though Cox expressed the Hemlock Society's sentiments that patients ought not be made to feel as though they were not actors in their own lives and deaths, the reactions to the society from the medical community at this time that were documented fall in line that supporting or facilitating euthanasia is "repugnant" and that it goes against the ethics of the medical profession. There was also still a belief from the medical community at this stage that "there is no reason in this day and age for a patient to have unbearable suffering."³⁸

Though the Hemlock Society was still strongly advocating for patient autonomy at this time, it was much more willing to acknowledge the tangible barriers to this autonomy and the

³⁷ Humphry, Derek. "The Case for Physician Assisted Suicide ." *Euthanasia Guidance and Research Organization* , Derek Humphry , 1995, www.finalexit.org/essay_case_for_pas.html.

³⁸ Cox, 1993. Page 35

damages these barriers created in the medical community and trust amongst patients and doctors. The end of the middle stage of the Hemlock Society was marked by an awareness of medical technology barriers and medical relationships for patients experiencing terminal illness. The emphasis is still on the patient's needs over those of the patient's caregivers though. The beginning of the Hemlock Society's middle stage was characterized by medical technology and protocol recommendations for terminally ill patients to pursue self-deliverance on their own outside of the medical system and illegally. There was a noticeable shift in this period of accountability of the society to acknowledge the needs of doctors and to branch outside of the limited communication of self-deliverance being the main/only factor for dignified death. This organization was still at its core extremely patient-centric and advocated mainly for active euthanasia as a dignified death in terminal illness.

Late Stage Hemlock Society: "Farewell to Hemlock - Killed By Its Name - Assisted Suicide", 2005

In the late period of existence, the Hemlock Society was involved in advocacy work to influence policy and litigate for death with dignity acts to legalize physician assisted suicide. This awareness and involvement demonstrates a stark difference from the earlier phases of the society in which patient care and education was prioritized.

"Farewell to Hemlock" was the last publication from the Hemlock Society while it was still an official advocacy organization. The Hemlock Society was dissolved on June 13, 2003 in Denver, Colorado, due to disagreements in leadership and advocacy goals. The group's legacy was reflected in its motto of "Good Life, Good Death." Derek Humphry lamented the end of the organization in this piece and reflected on its accomplishments over its 23-year existence. The Hemlock Society created a highly visible national platform for the DWD movement to have a voice and garner interest and awareness. This voice was loud and opinionated in its support of patient control and dignity above all else. Had the Hemlock Society not filled the space that it did,

the DWD movement in the US may not have gained the awareness and support that it did to strongly buttress it into the legal arenas in future years. Though it was a controversial and even inflammatory organization, the Hemlock Society was vital to the progress of the death with dignity movement and the development of effective advocacy for terminally ill patients.

Humphry, in his final chronicling of the Hemlock Society's stances and accomplishments, Humphry claimed that the Hemlock Society aided in drafting and launching the first model law governing euthanasia and assisted suicide in the US. He could mean that the organization's writings influenced policy makers or that lobbyists from the organization directly persuaded policy makers. This model law and other influential pieces from the Hemlock Society supposedly influenced the creation of a death with dignity act in Oregon passed in and debated in California, Washington, Michigan, and Maine but not passed in the late 1990's.

Humphry's final remarks on the death with dignity movement through the mouthpiece of the Hemlock Society were that people should not have to die alone or in agony and that people deserve the "opportunity to bring about peaceful ends when dying, trapped in a ruin body, or just plain terminally old, frail, and tired of life."³⁹ He still stressed that people need thoughtful and communally discussed reasons for pursuing rational suicide and that a dignified death should never be committed violently, involuntarily, or alone.

Conclusion:

To comment on the evolution of conceptualizations of death with dignity, it is important to first discuss how the Hemlock Society prioritized and framed dignity in its work. At the crux of the larger death with dignity movement was the idea that a patient was owed this vague and yet fundamental concept of dignity in all stages of life, including death. This society was interesting in

³⁹ Humphry, Derek. "Farewell to Hemlock - Killed By Its Name - Assisted Suicide." *Assisted Suicide Laws Around the World - Assisted Suicide*, Euthanasia Research & Guidance Organization, 21 Feb. 2004, www.assistedsuicide.org/farewell-to-hemlock.html.

that the bulk of conversation on dignity was centered around dying. Dignity crept in through discussions of how to end a life humanely and effectively so that a patient is not alone or suffering additionally. This was particularly evident in the repeated belief of the Hemlock Society that death should never occur alone, violently, or involuntarily.

The Hemlock Society did address in its writings the idea that dignity was also an important factor in the life of the patient; however, this was also framed by the death of the patient. The society asserted at a certain stage in its career that it was unfair for the law to penalize those who were seeking death in the face of a terrible illness. This position was indicative of dignity also meaning not having to hide behind closed doors in the process of dying. It was undignified to make a process fundamental to the society's beliefs on dignity illegal and inherently undignified. This was most of the Hemlock Society's commentary on policy and legalization as a concept of DWD. They did not work to change legislation around DWD so much as they complained that the laws preventing DWD were unjust and caused harm.

If the Hemlock Society's advocacy over its twenty-year career had to be summed up in two terms, they would be patient-centric and death-centric. To elaborate on the first chosen term, the society repeatedly expressed that a patient's needs and personal goals should supersede their doctors'. This comprises the Hemlock Society's views on what the patient and physician relationship should be like to facilitate dignity in terminal illness. Particularly in the early and mid-years, the society wrote that a caregiver ought to put aside their personal issues with the Hippocratic Oath and with their identity as a life saver and help patients to end their lives when the time is right for the patient. This perspective coupled with the belief that the patient can also flaunt the law when seeking out self-deliverance show that the patient's needs and goals are held in the highest regard by the Hemlock Society. The patient is always the priority of the society in its extensive career, and this could also be exacerbated by the fact that the Hemlock Society had 40,000 members across the country in its peak. These members are all fair game to be terminally ill patients at some point as are their family members and friends. The society gained its following

because these members felt some degree of affinity to the idea that their needs should come first in the event of terminal illness. The society maintains that patients should come first throughout its existence but also incorporates the needs of caregivers into their framework in their middle to later stages. This change occurred most likely because of the burden witnessed to doctors who were asked to be involved in patient's deaths and because of the repeated ugly and highly public court cases on a national platform that involved prosecution of those who aided in the deaths of terminally ill patients.⁴⁰

The second term to describe the Hemlock Society is death-centric. This term may seem to have a negative connotation, but it ought not when dealing with the Hemlock Society. This term was chosen because the Hemlock Society repeatedly gives advice and wisdom on how to plan for death and how to achieve a dignified death in terminal illness but does not express much support or advice on palliative care and other supportive technologies and treatments in terminal illness. Even when the society is discussing passive euthanasia in its early days, there is discussion of how to let someone die by removing nutrition or curative treatments but limited discussion of pain management or suffering management in the event that a patient chooses to die in an un-accelerated way or naturally. There is acknowledgment that this exists in the medical field and that patient's wishes are variable, but there is almost no recommendation for how to achieve a dignified natural death with terminal illness. The information disseminated by the society throughout its career explicitly centers on empowering patients to be assertive about their goals for end of life and educating them on how to achieve death when that is the goal.

This doesn't mean, though, that the society's scope of dignity and death with dignity was limited. On the contrary, this was advanced at the advent of the death with dignity movement in America. Facilitating a platform for patients to pursue any alternative to dying at the rate the medical system would allow was radical and diverse in the 1980's and into the 90's. This organization was the first mouthpiece for patients to hear about and express desire or opportunity

⁴⁰ Humphry, D. (1992). *Dying with dignity: Understanding euthanasia*. Secaucus, N.J: Carol Pub. Group.

for a dignified self-determined death on a large platform rather than whispered illegitimately in private. For that alone, the Hemlock Society's death-centric culture was invaluable for disrupting the status quo of terminal illness in America and allowing patients and health care providers the opportunity to talk about and even pursue alternative forms of treatment at the end of life. This organization is the only one that will be discussed in this research that is a dominantly death-centric entity, but without this early death with dignity advocacy and culture, there would not be a way paved for future organizations to shift awareness into palliative care, advanced technologies for support and relief in terminal illness, and future legislation to change the legality of these treatments.

Chapter Two

Compassion in Dying: Plunging Ahead in Legislative Changes and Support Care

The Hemlock Society set a strong foundation for awareness of suffering in terminal illness and the options available to address that suffering in patient and doctor relationship, legal and policy factors, and medical technology and protocol. This initial foundation was critical for death with dignity awareness, but it was only a preliminary stage of death with dignity advocacy in the US. The next wave of change in advocacy for terminally ill persons came with the organization Compassion in Dying. When Compassion in Dying was founded in 1993, the founders could have followed the example and infrastructure created by the Hemlock Society because it seemed to be successfully spreading across the nation and growing membership; however, they opted for a different approach to advocating for terminally ill patients' end of life support. Where the Hemlock Society emphasized that people have the option to take their life in the event of unbearable terminal illness regardless of the support level of the medical staff aiding that person, Compassion in Dying advocated for integrating patient needs into the care plan of the medical system and pushed for changes to the law to expand options within the medical system.

The genesis of this goal shift in advocacy with Compassion in Dying can be traced to the leadership of the organization and the medical and legal climate that it arose in. Compassion in Dying was founded in Seattle in 1993 by a physician, a hospice nurse, clergy members, social workers, and other social service professionals. This group differed significantly from Hemlock Society's leadership, which did not include anyone who worked directly in the medical field. The key founders in this list who were responsible for most of the literature and public facing work of Compassion in Dying were Barbara Coombs Lee and Timothy Quill. Coombs Lee has had career experience as a physician's assistant and nurse and often worked with terminally ill patients. This experience alone put her in a position to advocate for patients with a specific awareness for how to integrate advocacy directly into the medical care of the patients. In addition to her experience

directly in the medical field, Coombs Lee is also a JD and staffed the Oregon Senate Bioethics committee in 1991 in addition to other work to inform Oregon senators on healthcare matters.⁴¹ Quill has had a lifelong career in palliative care medicine and education.⁴² Like the founders of the Hemlock Society, Coombs Lee and Quill saw gaps in the care opportunities for terminally ill people, but they had perceived those gaps through a different lens than Humphry and Larue. The lens of the medical profession was drastically different than the lens of grieving family member and grief counselor and this caused the method of advocacy to be different in this organization.

The mission of Compassion in Dying was to “provide information, consultation, and emotional support to terminally-ill, mentally competent adults who wished to hasten death in the face of intolerable suffering.”⁴³ According to Quill, there was a lack of “open, honest guidance and support to those who wished not only to exhaust medical options to relieve symptoms, but also to consider hastened death as an option of last resort”.⁴⁴ This initial foray into the mission of the organization strongly suggests the direction of advocacy work of the organization that will be described in this chapter. Compassion in Dying focused on the suffering of terminally ill people and communicating fully with them about the options that are available in treatment at the end of life. Compassion in Dying’s advocates communicated honestly and openly with people about the full range of curative, palliative, hospice, and lifestyle options for finding relief in their illness. They strongly encourage patients to try these options before considering voluntary death as an option of last resort. They also worked directly with patients to actively facilitate these treatments within the bounds of the medical community’s ability for reformation of the law so that these options could be pursued legally. This approach was a stark departure from the advocacy work of the Hemlock Society in which Physician Aided Dying was the main tenant of death with dignity awareness and the patient was handled at a distance from the organization.

⁴¹ Barbara Coombs Lee, PA, FNP, JD.” *Compassion & Choices*, 2019, compassionandchoices.org/about-us/leadership-board-committees/our-leadership/barbara-coombs-lee/.

⁴² “Timothy Edward Quill, M.D.” *Referring Physicians*, University of Rochester Medical Center, 2019, www.urmc.rochester.edu/people/23067752-timothy-edward-quill.

⁴³ Merino, N. (2015). Ethics. Physician-assisted dying is justified by accepted ethical principles as explained by Barbara Coombs Lee. Page 190

⁴⁴ Physician Assisted Dying, 2015. Page 190

This organization had a small presence initially in 1993, but it spread to a national platform of advocacy and help. People from all over the country reached out to the organization when they needed help or reassurance in pursuing their end of life treatment options and they found solace. As of 2004, Compassion in Dying had data on interactions with 2,992 people across the US who had solicited the organization's help in the event of terminal illness.⁴⁵ Of the patients who solicited help from Compassion in Dying who were terminally ill, 291 died by assisted dying methods. The mean time from initiation of contact with the organization to death was 243 days.⁴⁶ Initially, AIDS was the most common condition of people seeking Compassion in Dying's help, but in later years cancer superseded AIDS as the main ailment present in the organization's clients. This information is available because Compassion in Dying's offices and administrators mandated that strict records were kept of all the organization's work.

The method for advocacy in this organization was an important factor for why it was successful in helping people and why it gained awareness and involvement during its existence. According to Coombs Lee's testimonies in *Caring for the Dying*, Compassion in Dying had a very structured hierarchy of operation to promote efficient and caring advocacy.⁴⁷ When patients reached out to the organization, a specific advocate took on their case and acted as a liaison to the person in their treatment and illness but the advocate was also meant to be a friend and companion during their illness. The patient consulted with their liaison and narrated their story of their life before disease, their disease, their treatment, and any other pertinent information about how the disease had affected their life and their lifestyle. The liaison then explored and communicated with their patient about what the person's treatment goals were. After reaching an understanding about the state of the person's life and illness at the stage when they contacted the advocacy group, the assigned advocate then communicated with the patient and, if given permission, communicated with the care team surrounding the patient, including doctors, nurses,

⁴⁵ Physician Assisted Dying, 2015. Page 194

⁴⁶ Physician Assisted Dying, 2015. Page 194

⁴⁷ Baird, R. M., & Rosenbaum, S. E. (2003). Palliative Treatments of Last Resort: Choosing the Least Harmful Alternatives. In *Caring for the dying: Critical issues at the edge of life* (pp 99-116). Amherst, N.Y: Prometheus Books. Chapter on Palliative treatments of last resort : choosing the least harmful alternative / Timothy E. Quill, Barbara Coombs Lee, Sally Nunn -- Caring for the dying : congressional mischief.

hospice workers, family, spiritual leaders, etcetera. The options for care were then discussed utilizing the full breadth of Compassion in Dying's resources, research, and clinical experience in working with terminal illness.

The advocate was ultimately empowering and supporting their patient in pursuing the medical and personal treatment that the patient wanted or needed to align with what experience for dignity and life that they wanted to lead up to their death. The care team was the group that facilitated the actions and the technical treatments that satisfied these goals. Importantly, the patient set the goals and chose what avenue of treatment they want. The advocate also communicated to the patient that they have a very large range of medical options available to them including assisted death, but not beginning with assisted death. The advocates worked with patients on pursuing physician-assisted death in states where was not legal and facilitated communication for the patient in a way that lead to more cooperation with doctors and care teams than the Hemlock Society's methods did. The work of Compassion in Dying led to a new era of death with dignity treatment and advocacy that consisted of an integrated effort from both doctors and patients to reach the same goals in end of life care and an expanded consensus about the need to change medical practice to accommodate the needs of dying patients beyond curative treatment. The collaboration between patients, advocates, and care teams was a stark departure from previous advocacy styles. The work that Compassion in Dying did in policy and legal advocacy for death with dignity medical advancement was another distinct shift that this group brought to the death with dignity field.

Physician Assisted Dying is a compilation of expert opinions in the various fields affiliated with physician assisted death demonstrated the full range of information on this practice as of 2003. The selected chapter from this piece was written by Compassion in Dying president, Barbara Coombs Lee. The initial phase of this organization showed that advocates in the organization worked to integrate the established medical caregivers of dying individuals into the plan of action for end of life of the ill person. This approach was a shift from the Hemlock Society's stance that the caregivers need not be fully involved in the end of life plans of the patient, especially when the patient's views and goals for end of life treatment didn't align with the

physician's. There was also a shift in this literature with the preliminary requirements for physician aided death delineated by Coombs Lee and the organization. These requirements were part of the Oregon Death with Dignity Act which was co-authored by Coombs Lee. The most prominent medical technology in this era of advocacy to achieve dignity for the terminally ill was adequate pain management and maximization of palliative care treatment in conjunction with hospice with physician assisted death being a treatment of last resort in severe cases of terminal illness and suffering.

In the chapter of *Caring for the Dying* analyzed in this chapter, Barbara Coombs Lee along with Timothy E. Quill, and Sally Nunn represent the voice of the University of Pennsylvania's Center for Bioethics Assisted Suicide Consensus Panel and the Compassion in Dying Federation, which Coombs was president of. The main thread of discussion and argument through this writing piece is that there were multiple options for patients to seek for treatment and care in their terminal illness and their dying stages. These care options were diverse in technical delivery and patient impact, but they all emphasized that ending treatment or transitioning into the death phase of end of life medicine were last resort measures and should be handled on a case by case basis and with extreme care.

The medical practices that were discussed in *Caring for the Dying* were standard pain management, forgoing life sustaining therapy, voluntarily terminating food and hydration delivery, terminal sedation, and physician-assisted suicide. Coombs Lee along with Quill and Nunning created comprehension about the medical delivery and patient outcome of these practices through short case study examples of patients who received and subsequently passed away from each of these DWD practices. It should also be noted that all the practices discussed in this piece were death with dignity practices because they facilitated patients who were terminally ill passing away in ways that benefited their communicated desires and fit with their framework of values and needs. These case studies all emphasized the patient's views and desires and documented the decision process that led to the patient receiving their therapy of choice.

Euthanasia reflects the state of Compassion in Dying in the latter stages of their existence at 2005. Quill reiterated here that terminally ill people should fully integrate their goals

and care plan for end of life with the care plan of their medical care givers. This means that the caregivers ought to accommodate the needs of the patient as much as possible and this meant exhausting all care options available up to the point of physician aided dying as care of last resort.

The medical protocol and technology that facilitated maximizing care and comfort for terminally ill persons emphasized giving patients enough pain medication to fully manage symptoms, facilitating comprehensive palliative care, making hospice available and personal for people, and using physician aided dying if and only if all these options fail to provide a person relief and the will to live in their illness. This approach was facilitated fully in Oregon at this time due to the enactment and usage of the ODDA but it was not in other states. Quill explained that there are alternative options for patients to seek a dignified death outside of physician assisted dying within the bounds of the law but that there are illegal and contentious issues within the medical and legal practice at this time. On this note, Compassion in Dying made a strong effort to end the language use of physician assisted suicide and move to language of physician assisted dying due to the negative societal connotation with the word suicide.

To support my claims that Compassion in Dying's impact on death with dignity advocacy was a dramatic shift of cooperation between patient and medical sphere and that they drastically changed the policy-scape for physician-aided death, I have selected three primary sources from the organization that together comprehensively illustrate the organization's approach to advocacy. Other materials from the organization reiterate the information in these works. Drawing on the three sources, I explain how the organization's advocacy and conceptualizations of DWD change from 2003 to 2005. In particular, I will describe how the physician and patient relationship, medical policy on DWD, and medical protocols and technologies shaped or were shaped by the organization's ideas of DWD. This organization spanned the shortest period of the groups in this research, but it had the most rapid and dramatic impact on the conceptualizations of death with dignity and methods for advocacy influence of the groups discussed in this study. This group advocated for a marriage between the patient's needs and their care plan for that patient. They also promoted policy facilitating better access to physician aided dying.

Physician and Patient Relationship Factors:

Compassion in Dying operated in states that did not legally allow for assisted dying in the case of terminal illness, so this affected the relationship dynamic that the organization had with patients and their caregivers as well as the dynamic between patients and their caregivers.

Barbara Coombs Lee wrote about cases in which terminally ill people contacted the organization, from states where assisted suicide was not legal, to ask for consultations on their illness and their candidacy status for assisted suicide. An advocate would have a detailed conversation with the patient and any family members and doctors the patient wished to include.⁴⁸ In these conversations, the advocate assessed the patient's eligibility for assisted death, as determined by the organization's guidelines (see next section), the advocate explained if the patient qualified for assisted death, the advocate explained how to achieve that using all the organization's available and pertinent resources. The plans provided by the advocate included options for adequate pain management, symptom control, communication plans with the care teams, and, finally, in the case of last resort, a report on how to seek medication from the attending physician to end life in a humane manner proven to be effective by the organization's research and protocol data.

In the cases reported by Compassion in Dying in this chapter, the caregivers of the patients were cooperative with prescribing a medication in a dose that could be life ending if taken all at once after they had consulted with the patient's liaison at Compassion in Dying. The direct communication and involvement with this advocacy group seemed to ease physician's nerves about aiding patients in this particular brand of care. This willingness of physicians to help patients in their death was also a product of the advocacy group's insistence that the patient pursues all palliative options to the point of severe discomfort and inability to live with their illness any longer and under the assurance that the patient will administer the medication to themselves.

⁴⁸ Quill, T. E., & Battin, M. P. (2004). A Model That Integrates Assisted Dying with Excellent End-of-Life Care. In *Physician-assisted dying: The case for palliative care and patient choice* (pp190-201). Baltimore, Md: Johns Hopkins University Press. A group of specialists in different fields comes together to counter the arguments against legalizing physician assisted suicide. Coombs Lee is one of the voices.

This dynamic between terminally-ill people and their doctors was slightly different in communities where physician-assisted suicide was legal. Physicians still might not communicate all the patient's options clearly in a way that the patient understood that their illness was terminal and that death would be the end outcome of the illness. Poor communication could have meant that patients relied on curative treatments past the point where their illness was curable and suffered physically from the morbidities affiliated with those treatments as well as manifested a false sense of hope that they would recover from the illness. Miscommunicating the prognosis of an illness might not have been a malicious move on the physician's part but rather a reluctance to admit defeat to the illness. When palliative care was pursued finally in the cases of terminal illness in legal states, advocacy groups and hospice workers could inform a patient that physician-assisted dying is a legal option in their state and patients may make a decision about that treatment. If the patient did want to pursue assisted dying and their physician was willing and licensed to assist them through the legal process of procuring a lethal dosage of barbiturates per the parameters of the law, then the physician started the patient in the paperwork process of securing this medication and followed them past the point of dying. After the patient was deceased, the physician filled out and submitted compliance forms on the patient's treatment per the state health department in Oregon at this time, and other states as they individually pass death with dignity acts.

In the states where physician-assisted dying was legal, physicians and psychologists evaluated a patient and gave their professional opinion that the patient qualified for assisted dying and was of sound mind when requesting assisted death. When the patient received their medication for assisted dying, the physician was not legally mandated to be present when the medication was taken, and the physician could not legally administer the medication to the patient. The patient had to administer the medication to themselves.

In *Caring for the Dying*, a clinical vignette is used to show how a primary care provider suggested full pain management treatment to the patient in the case study as an option to control the painful symptoms of their late stage metastatic lung cancer. The patient had already switched

their treatment plan over to palliative care and had acknowledged with their caregivers that this disease would not be recovered from. The physician increased the patient's opioid dose 25 percent after discussion and maintained that level until the patient was comfortable and then subsequently lost consciousness until death two days later. The physician managed the patient's pain medicine dosage throughout this process.

In the case of withdrawing lifesaving therapies, the primary physician was also the individual who identified and communicated to the patient that this plan of action was available in their case. The patient was in late stage brain cancer and had already attempted to commit suicide due to reported loss of comfort and meaning in life. The physician identified that the patient no longer wanted to live and that the medications that the patient was being prescribed were prolonging his life. The patient agreed that it was best to cease that medication usage and passed twenty-four hours later.⁴⁹ The commentary for this case emphasizes that there needs to be a thorough discussion with all caregivers about the balanced effects of palliative healthcare, daily quality of life, and suffering levels of the patients before the patient can be ethically and reasonably permitted to pursue this protocol. The medical doctor did mitigate this process for the patient though and ultimately satisfied the patient's wishes more acutely than when they were treating the patients' symptoms because the physician listened to the patient's verbal and nonverbal language on their outlook of their condition.

In the case study shared involving voluntary termination of eating and drinking, the patient had been pursuing palliative care for over a year and communicated in earnest for months thereafter that she wanted to die and was prepared to die. The patient in this case initiated discussions about ceasing nutrition with family and the primary physician. Many members of the supporting care staff refused to support and aid the patient in this endeavor and were subsequently removed from her care. The patient's doctors and care team all had to commit to helping the patient through her fifteen-day dying process after deciding to end nutrition. They kept her externally hydrated and comfortable and all agreed to refuse to attempt to give nutrition. This

⁴⁹ Coombs Lee, Barbara (2003). *Compassion in dying: Stories of dignity and choice*. Troutdale, Or: NewSage Press. A series of stories and vignettes about patients' spirituality and experiences in the dying process.

case is important because it is a prolonged dying process that can be easily construed as causing suffering to the patient, but the caregivers all commit to maintaining the process because they are aware of the patient's wishes to be successful in this process regardless of the expected struggle. There is an underlying commentary here that the suffering of enduring this dying process is a tradeoff that the patient has chosen in lieu of the suffering inflicted by their illness for an unknown amount of time if the dying process is not pursued. This choice is respected.

In the case study shared involving terminal sedation, the patient spent a prolonged period in hospice after it was made clear that they would not recover from their AIDS. After spending that time in hospice with supportive care, the patient still was not able to find any reprieve from their pain and shortness of breath. An unidentified member of the patient's care team suggested terminal sedation and the patient chose to pursue it. The patient's physician gave them a dosage of a sedative in an upward titration until the patient was unconscious and appeared to be restful and this dosage was maintained until the patient passed three days later. The physicians watched the patient to make sure there were no signs of discomfort during the patient's unconsciousness.

In the case shared involving physician-assisted dying, the patient in question was dealing with a throat tumor that was threatening to rupture and suffocate them to death. The patient was offered pain management, terminal sedation, and cessation of nutrition by their physician but declined all because they were fearful that the treatments would not relieve them of the threat of suffocation. The patient entreated their primary physician to give them an option that ended their life peacefully and on their terms before suffocation did. The physician consulted with the other members of their practice and then gave the patient a prescription of barbiturates under the guise that it was to help the patient sleep. The physician declined to be present when the medication was consumed to avoid liability but was on call in case of complication. There were no complications and the patient passed from the medication. The physician in this case was empathetic to the patient's morbid and justified fear of suffocation and did try to offer the patient alternative treatments before agreeing to aid the patient in ending their life out of respect for the patient.

In *Euthanasia*, Quill shared his valuable insight as a primary care and palliation physician into how patients' lives were affected by terminal illness and what role their physicians played in ameliorating the suffering of that illness. Through first-hand accounts of working with terminally ill patients, Quill articulated that it was the role of the patient's physician to step in and be a source of support when terminal illness was diagnosed. He acknowledged that not all illness seems like terminal illness at first and that patients often wanted to approach their diagnosis as if it were treatable and explored all options available to them. It was important to preserve the dignity of the patient in those circumstances fully discussing the likely outcomes of the illness, and this conversation should include addressing death as a possible outcome if clinical experience indicated that it was indeed a reality. Quill states that it is important in the Death with Dignity realm of medicine to acknowledge that "sometimes the very interventions we use to keep people alive longer indirectly prolong their dying."⁵⁰ The distinction between extending life and prolonging dying is not always easy to see but it is important to question at all times when working with patients facing terminal illness.

In this era, Quill advocated for assisted dying as last resort in terminal illness, but he asserted that all other options ought to be exhausted fully before this recourse was taken. From his experience with hospice care, Quill stated that the attending physician should get to know a patient as much as possible in this final stage of life to give them ideal care. A prime example of this approach being critical was the example that Quill gave in this chapter of his care for a Buddhist woman coping with fatal gastric cancer. It was vital that her physician (Quill) understand her spirituality and her community in order to understand that the way she died mattered to her because it would affect the way she was reborn in her next life according to her beliefs. This belief system meant that the woman wanted to die as peacefully and with as little indignity as possible. In the event of her developing a festering, open sore on her abdomen from her feeding system, she requested that Quill aid her in passing by increasing her sedative dosage until she was no longer cognizant of her suffering. She passed shortly after this event surrounded by her

⁵⁰ Medina, Loretta M. "Chapter 4.4: When Palliative Care Fails, Assisted Suicide Should Be an Option." *Euthanasia*, edited by Quill E Timothy, Thomson Gale, 2005, pp. 196–204.
Page 197

community and on her own terms. Quill, and Compassion in Dying as an extension, believed that it was the physician's responsibility to give patients the opportunity to die with their sense of dignity intact, even to the extent of aiding that patient in dying, after all their palliative and curative care options were exhausted.

Legal and Policy Factors:

In *Physician Assisted Dying*, Compassion in Dying's advocacy to conceptualize DWD in terms of legal and policy factors is characterized by the organization's involvement to legalize physician-assisted death in Oregon. Compassion in Dying's founders, including Barbara Coombs Lee, directly aided in writing the Oregon Death with Dignity Act early drafts up through the final and they helped implement the law once it was voted in.

The founders of Compassion in Dying believed that mentally competent adults who were terminally ill needed to be allowed to pursue their end-of-life care options in the full spectrum that those options existed in. This meant that dying on one's own terms needed to become legally available to be humanely conducted because it was considered one of the options for a dignified death. Compassion in Dying created a set of eligibility criteria that informed its members of when they could rationally consider assisted death as a last resort treatment. This document was ultimately codified in the Oregon Death with Dignity Act (ODDA) and was one of the early documents in the US to legally delineate how assisted dying should be reasonably self-administered. The eligibility requirements from that document were these:

- A medical evaluation has determined the patient's condition is, in reasonable medical judgment, likely to result in death within six months
- The patient is an adult who is competent to make healthcare decisions and does not exhibit pathological depression or other mental impairment that affects judgment
- The patient's condition causes suffering that is severe and intolerable to the patient
- The patient's suffering does not result from inadequate comfort care, especially inadequate pain management

- The patient has a firm understanding of the diagnosis, prognosis, and available interventions in palliative care
- The patient has originated the request for information about assisted dying, put it in writing or on videotape, and repeated it over time. The request is voluntary, rational, and enduring. Inadequate health insurance or economic concerns do not motivate the request.
- Requests cannot be made through an advanced directive or surrogate decision maker
- There is no expressed disapproval from any member of the immediate family.

These guidelines were written in 1995 and revised in 1997 with the passing of the Oregon Death with Dignity Act.⁵¹ At the time that Compassion in Dying was founded, assisted dying was not legal anywhere in the country. The organization offered consultation to patients who resided in places where assisted dying was legal as well as places where it was not legal. Compassion in Dying's name can add some context to the way that they address the legal system in regard to death with dignity options. They did not assert that physician aided dying was the first or primary recourse that should be taken when a person is suffering with terminal illness, but they did not think that it should be a punishable or unavailable recourse either. Compassion in Dying directly influenced the passing of the Oregon Death with Dignity Act in the 1990's through its advocacy workers in lobbying and awareness. The founders of this organization had firsthand experience with watching people die of terminal illness in a medical system that was limited on the help it could legally offer people. The founders and leaders of this organization were also influenced in their stances on physician-assisted dying by their witnessing of patients asking for help in dying covertly outside of the legal bounds of the medical system. These undocumented and illicit cases had a variable range of outcomes for the patients and their families. When discussing the legalization of physician-assisted dying in the medical system, Compassion in Dying explained

⁵¹ Quill, T. E., & Battin, M. P. (2004). A Model That Integrates Assisted Dying with Excellent End-of-Life Care. In *Physician-assisted dying: The case for palliative care and patient choice* (pp190-201). Baltimore, Md: Johns Hopkins University Press. A group of specialists in different fields comes together to counter the arguments against legalizing physician assisted suicide. Coombs Lee is one of the voices.
Page 192

that, “Evidence of widespread covert assisted dying, compared with Oregon’s experience with regulation, suggests that legally recognizing physician-assisted death as legitimate medical practice might have the unexpected effect of reducing its incidence.”⁵² At the time of this piece’s publication, only one state had legalized physician-assisted death but Compassion in Dying was still advocating for legalization in other states.

Caring for the Dying was published in 2003 when death with dignity practices were limited legally. At this time, all of the listed practices except for physician-assisted suicide (PAS) were legal under an approved variety of circumstances. Legality was only a barrier to treatment in the case of the patient who requested physician-assisted suicide to avoid suffocation. At this time, PAS was legal in Oregon only in the United States and this case did not take place in Oregon. The physician did have to risk their legal security to give the patient their desired medication. It should also be noted that this case and other cases of covert PAS do not get to be documented and regulated the ways that legal cases of PAS are documented and regulated. This also affects the academic and medical community’s awareness and understanding of how PAS is administered and who receives it.

In 2005 when Quill wrote this excerpt in *Euthanasia*, Death with Dignity Acts legalizing physician-assisted suicide had not been passed anywhere other than Oregon. This lack did not mean that a patient could not legally seek assisted dying within the limits of the law in other states. At this stage, Quill acknowledged both cessation of nutrition/hydration and increase of painkillers and sedatives (not to a fatal dosage but just an increase to the point of being not lucid) as legal and acceptable forms of assisted death or self-determined death for terminally ill people. Compassion in Dying and Quill did not assert that these are not ideal ways for people to pass. They were saying that the medical and legal communities meant to support terminally ill people could do better to aid in dignified death, but these passive euthanasia options were the options available at this time.

Quill hinted at a tension between the medical community and policy makers in this area. He made it seem like the medical community that treated people with terminal illness, including

⁵² Quill and Battin, 2004. Page 199

hospice agencies, understand different options need to be available for terminally ill people to treat them until and into death. Some in these communities would even say not just that different options are needed, but better ones too. The options that Quill was speaking about were increasing pain medications for palliation even at the risk of incrementally increasing them to a fatal dose to alleviate suffering and explicitly prescribing a lethal dose of medication that was intended to end life at the time when the patient was no longer willing to endure their suffering. This latter option can be called physician-assisted dying in legal vernacular, but Quill insisted that "suicide is not the right word to use in these conversations; it is correct technically but incorrect from a meaning point of view. Suicide, or self-killing, has a connotation destruction of self. People requesting a doctor's' assistance in dying feel that their personhood, their very self, is being destroyed by the illness."⁵³ This dynamic meant that the legalization of assisted death by lethal medication dosage would be a salvation to those suffering in terminal illness rather than a destruction of morality in the medical field. This discrepancy between salvation and destruction is the tension between the medical field and legal field that Quill was hinting at.

Compassion in Dying was actively engaged in the national policy debate over the accessibility of death with dignity practices. Quill stated, "The current national policy debate focuses on methods of response to ... explicit decisions"⁵⁴ about ending one's life when terminally ill. The explicit decisions referred to here are the decisions that patients make after comprehensive discussions with their doctor about how to proceed in their end of life care. Policy did not allow in most places that these conversations include a dialogue on choosing to die when ready, but Quill explained that comprehensive care and support cannot be given without the inclusion of this dialogue. Patients were mostly often given some information that death may be an effect of their disease or that death may result even from the aggressive treatments for their disease, but the explicit conversation about the technical mechanisms of the death and options for how to approach and receive this event were limited in legal advancement and application at

⁵³ Medina and Quill, 2005. Page 201

⁵⁴ Medina and Quill, 2005. Page 200

this stage in history. Again, Compassion in Dying was involved at this stage in legal advocacy to affect change to the status quo.

Medical Technologies and Protocols:

The technology in question for Compassion in Dying's advocacy efforts was adequate pain management in palliative care for patients up until the point that the patient's symptoms can no longer be managed and physician-assisted death is the only reasonable option for that patient. Coombs Lee iterated in this chapter of *Physician Assisted Dying* and in other writing that part of the reason patients became desperate and felt like they were losing their dignity at the end of life was because their symptoms were not well managed by their caregivers. Coombs Lee documented reluctance in the medical community to increase morphine and other pain medication dosages for terminally ill patients due to an increasing awareness for addiction and morbidities from pain meds. This point was addressed from multiple angles and was a recurring issue in the Compassion in Dying's text of the early 2000's; however, the writers from this group continually claimed that addiction was not something that the medical community should be concerned about in the case of dying patients. Quill and Coombs Lee both explained when a terminally ill patient is continually asking for higher doses of morphine and other pain managers, it's not because that patient is building tolerance and is craving the medication. Rather, the patient is experiencing ever increasing levels of pain with each level being less bearable than the last and the patient is craving reprieve from the excruciating deterioration of their body. The obsession of the patient is with pain and not the meds whereas the obsession of an addict is with the meds and the sensation of the meds. Furthermore, these patients cannot hope to have a life after the illness, so the social implications of addiction do not apply to them.

The crux of this problem was not whether terminally ill people were becoming addicted to morphine, but that the medical community was not adequately managing the pain symptoms of terminally ill patients. It was critical in all terminal illness that pain management be prioritized and continually addressed and updated to meet the patient's needs because a patient who was in ongoing pain had lesser quality of life at the end of life. Patients suffering in pain while they're

dying because doctors are weary of giving them pain medication was a failure of the medical system. The medical system had a duty to give terminal patients full palliative support and medical consultation in the end of life process, because this was the same medical system that did not legally offer terminally ill people the option to take their lives in a humane way in terminal illness. Managing the pain associated with terminal illness and the symptoms that lead to suffering and indignity was vital to giving terminal people quality of life. Coombs-Lee insisted that having a comprehensive conversation and subsequent care plan for patients with terminal illness about managing all their symptoms on a continual basis was what made these patients want to continue living and avoid an undignified dying process.

That being said, every case is nuanced and not every person's symptoms can be managed in a sufficient way. This is where Compassion in Dying is actively changing the medical field at this time. Barbara Coombs Lee uses a clinical case example to illustrate the process that Compassion in Dying engages in with terminally ill patients who seek out their advocacy services. Compassion in Dying engaged with patients through contact lines and opportunities laid out throughout the medical community, social work community, and legal community at all the points of interest for a terminally ill person receiving care for their illness. Once these contact points were engaged, the patient is partnered with a liaison in the organization who communicates with the patient about their life, illness, and current care regimen. After the patient's present state was understood and assessed, the liaison communicated with the patient and their care team about the organization's care recommendations, and in the event that the patient desired this option, the liaison would also discuss how to humanely and safely end the patient's life when the patient was ready. In the states where physician-assisted dying is legal, the organization connected the patient to the correct forms and chain of command that they needed to go through to receive the medication to end their life and stayed in contact and supported them throughout this process whether the patient decided to end their life or die of the illness. In the cases where the patient was in a state where physician-assisted dying is not legal, the advocacy contact advised the patient on how to seek cooperation from their doctor and gave them information on how to accumulate the right medications in the right doses to be taken at once to end their life.

The clinical case that Coombs Lee used as an example for this process was important because that patient went through the steps to secure life-ending medication in a state where assisted death was not legal, but the patient ultimately chose to die naturally and cited that she was relieved of her emotional suffering when she knew that she had the means to die at her own hand if she chose to. Additionally, her liaison at Compassion in Dying believed that “by addressing her fears and giving her a sense of control, it may have prolonged her life.”⁵⁵ Compassion in Dying did not assist patients with dying until all other care options were attempted and failed the patient in their time of need. They firmly asserted that the value for the patient was in having autonomy over their care to the extent that they could pursue all options including death. The value to the terminally ill person was not in dying, but in having the choice to die if that was the only and last relief for a person facing brutal end-of-life symptoms.

In each of the cases narrated in *Caring for the Dying*, palliative care was pursued before life ending treatment. Hospice was also included at some level as a care tactic in these cases, but in all cases the patients communicated that they wanted a different path of treatment and were obliged after dedicated discussion of their full range of options. In the case of pain management and terminal sedation, the patients relied on their caregivers’ expert knowledge of human physiology to know the thresholds to increase medication to and to maintain those levels in the realm of the patient’s comfort. In the case of termination of nutrition and hydration, the caregivers had to maintain the patient’s comfort without feeding them or giving them water. In this case, there was a delivery of pain killers and the patient’s mouth was kept moist with small amounts of water. The caregivers also applied lotion to the patient’s skin and made sure her limbs had circulation despite her listlessness and unconsciousness. The patient who received the barbiturate prescription to aid their medical suicide relied on their physician’s knowledge of lethal levels of sedative in the human body. If the prescribed pills were ingested individually, the patient would only have been sedated. The patient was advised indirectly to ingest all the pills at once for their intended purpose to be successful.

⁵⁵ Quill and Battin, 2004. Page 194

In *Euthanasia*, instead of discussing emerging technologies to guide DWD practices, Quill discussed how hospice and palliative care were important resources. The Compassion in Dying leadership repeatedly articulated this position. This organization promoted physician-assisted dying as a necessary option to fully support people with terminal illness, but they also continually asserted that all other methods of treatment must be exhausted before assisted-dying was pursued. As Barbara Coombs Lee explained earlier, hospice care and palliation were valuable tools to deliver relief and dignity to people with terminal illness, but these tools had limitations. Quill explains that "we tend to offer palliative care very late in an illness, when all else has failed-- we must learn to offer it earlier and deliver it longer. We still worry about addiction and overdose with pain medication, and doctors worry about being reviewed; these anxieties lead us to under medicate dying persons."⁵⁶

One of the medical protocols around terminal illness that Compassion in Dying voiced a critique of was that curative options were pursued and pushed by patients and their caregivers for too long past the point when curative treatments were valid treatment options. Hospice care and palliative care ought not be viewed as the option that was taken when care failed, but rather as the option that was taken to not fail the patient by robbing them quality of life at the inevitable end of life in terminal illness.

The scope of hospice care was to keep a patient comfortable at home or in a comfortable facility and to empower the family or other care team members of that person to be able to care for the patient without hospital staff present full time. Hospice included pain management, fluid and nutrition delivery to the patient's body in its different states, and any other physical needs the patient may have. Hospice care was meant to support the patient from when they left the hospital and their curative care regimen until the point of death. Hospice care also offered consultation for the patient and the patient's family on grief and how to proceed after the patient was deceased. It was an excellent and constantly improving tool for providing patients with more dignity and support for their human needs at the end of life outside of exclusively caring for their corporal needs.

⁵⁶ Medina and Quill, 2005. Page 200

Terminal illnesses did not only ravage the body. They could ravage the spirit of a person as well by preventing them from having a routine, preventing them from existing without pain, preventing them from performing basic tasks autonomously, such as eliminating waste and bathing, and preventing them from pursuing the activities that once made their life rich in meaning and value. Quill pointed to a poignant reality of the medical system when addressing bedside manner and realism in terminal illness instead of idealism when he explained that, "If we cannot talk about [the limitations of hospice care] our patients think we shall not face up to the extreme suffering if they are so unlucky as to experience it."⁵⁷ Patients who were suffering with terminal illness feared their deterioration and suffering that became the undertone of everyday life. They did not want to feel alone in this state, so they looked to their caregivers to be a source of support and relief. This did not mean that the lives of terminally ill people were of any less value due to their illness—it meant that the patient's view of the quality of their life was the most important view and ought to be respected in the eyes of Compassion in Dying. If a patient's quality of life deteriorated due to an illness to the point where the act of surviving every day is an undue burden even with pain management and hospice care, then that patient should not be forced to continue shouldering that burden. Quill stated that "Physician-assisted death is a narrow question to be raised only when good palliative care fails."⁵⁸ This is why Compassion in Choices included physician-assisted dying in its spectrum of terminal illness care options for patients. It was compassionate and responsible within this advocacy group to allow that opportunity to dying persons and to acknowledge that curative and palliative care was not the end of good care options in every circumstance. "Conversing about physician assistance in dying is reserved for cases in which we have gone through this process with the patient, and in which the patient's end-stage suffering is extreme and intolerable-- death is all that waits"⁵⁹ If death was all that waited the patient and there was no more quality of life to look forward to, it was undignified to and unfair to prioritize quantity of life for the patient as a third-party participant in the dying process.

⁵⁷ Medina and Quill, 2005. Page 200

⁵⁸ Medina and Quill, 2005. Page 200

⁵⁹ Medina and Quill, 2005. Page 198

Conclusion:

As a death with dignity advocacy organization, Compassion in Dying ushered in an era of collaboration in healthcare options between the medical community, the terminally ill, and the laws that govern assisted dying. Though death with dignity treatments and principles always act peripherally and within the medical community, Compassion in Dying left a legacy of directly collaborating with the medical community that surrounded its patients and integrating its own knowledge and care goals into the existing care plan of the medical groups it interacted with. Along with this direct communication with the medical system, Compassion in Dying crafted a specific hierarchy of care choices that it recommended to patients suffering with terminal illness. Compassion in Dying made an effort to rebrand assisted dying to undermine previous notions that a choice to die was synonymous with suicide. This group empowered terminally ill people and their medical care teams to consider end of life health care plans that had a more comprehensive spectrum of treatment options with assisted death as a last resort option after all treatment and palliative efforts had failed.

Coombs Lee comprehensively clarified Compassion in Dying's platform of advocacy for choices:

"Dying patients deserve the best we can offer in symptom management, adaptive technology, psychosocial support, and spiritual comfort. They also deserve a sense of control over the degree and duration of deterioration and suffering they endure. The choice of assisted dying gives patients that sense of control. Many never exercise the choice, but they can all experience a heightened sense of autonomy and peace of mind from knowing that it is theirs to make. Compassion in Dying's experience in Oregon and elsewhere suggests that suffering may be more tolerable when it is endured voluntarily. Peace of mind, endurance, patient autonomy—these are worthy goals for a healing profession. Integrating the choice of assisted dying into excellent end-of-life care helps achieve them."⁶⁰

Compassion in Dying conceptualized dignity as giving choices to patients that actually met the patient's needs. These choices were care and treatment technology options, different palliative care options and hospice support, choice to manage pain levels totally, and in the case of intolerable suffering there was the choice to actively end life. The empowerment of the patient that Compassion in Dying facilitated was also made possible by this organization's

⁶⁰ Quill and Battin, Physician Assisted Dying, 2004. Page 199

involvement in legalizing physician aided dying in Oregon and advocacy to make the medical system more harmonious with the social and moral imperatives surrounding terminally ill people's death with dignity desires and goals. Compassion in Dying's advocacy was very different from the Hemlock Society's advocacy and its conceptualizations of dignity at end of life were different but ultimately the crux of the argument is consistently that dying person's ought to be supported in their choices for how to exist and die at the end of life and that giving choice and power to the patient is one of the most effective ways to foster dignity and relief. Compassion and Choices will usher in the final piece of the modern death with dignity puzzle with their legal and policy work to legalize physician assisted death in more locations and their facilitation of more advanced protocol and technology in aided dying in the next chapter.

Chapter Three

Compassion and Choices: A Modern Take on Palliation and Relief

Compassion and Choices is the final organization in this study. Compassion and Choices was founded in 2007 when the remnants of the Hemlock Society and the thriving Compassion in Dying organizations merged. Compassion and Choices emerged with the intent of centralizing death with dignity advocacy in the US and with shifting the field of advocacy to embody their mission statement:

“Compassion & Choices improves care, expands options and empowers everyone to chart their end-of-life journey. We envision a society that affirms life and accepts the inevitability of death, embraces expanded options for compassionate dying, and empowers everyone to choose end-of-life care that reflects their values, priorities, and beliefs.”⁶¹

The important part of this mission statement that marks the Compassion and Choices’ new era of advocacy is that it “embraces expanded options for compassionate dying” and that it “empowers everyone to choose end-of-life care that reflects their values, priorities, and beliefs.”

Hemlock Society made people aware for the first time that physician aided death, or self-determination as they put it, is an available option for terminally ill persons but they did not commit to direct involvement with patients and they advocated for people working outside of the law and medical system when the medical system did not work with their wishes. Compassion in Dying created a structured system of advocacy with volunteers who directly interacted with terminally ill persons to create a care plan that works with that person’s needs. This group heavily advocated for palliative care and hospice care for dying persons but still facilitated physician assisted suicide as a treatment of last resort even in cases where it was not legal. Compassion and Choices built on the platform these organizations created and it launched a higher caliber advocacy platform to change legislation and policy to legalize physician-aided dying more universally.

Compassion and Choices is still in operation and is now the largest death with dignity advocacy group in the country. The reach of this organization in the medical community, caregiver support communities peripheral to caregivers, and legislative action is unprecedented

⁶¹ Compassion and Choices mission statement can be found at <https://compassionandchoices.org/about-us/>

and fuels this organization's mission to empower and educate people on their full range of options in end of life care. Along with creating more legislative opportunities to legalize physician aided death in more areas, Compassion and Choices also works to educate the public and the medical system on the tenets of dignity at the end of life and how dignity can be achieved.

The president of Compassion and Choices, Barbara Coombs Lee, is the primary mouthpiece for this organization. She is one of the key publishers in the organization and one of the longest standing advocates of the organization. Coombs has spent much energy on conveying to the public why dignity and end of life options are issues that should be embraced and debated openly and avidly. One of the more personable approaches she has used for explaining the necessity of death with dignity treatments is that, "We all expect to live with dignity. And we all deserve to die with dignity, too."⁶² Many of the Compassion and Choices arguments about death with dignity emphasize that the main reason people are owed dignity in death is because the suffering at the end of life should not overshadow or cause disrespect to the good life that a person lived. This rationale is important as well for understanding why empowering dying persons to end their life on their terms is an act of compassion in this organization rather than an act of cruelty and negligence as their opponents have stated.⁶³ In the publications of Compassion and Choices, authors repeatedly say in some form that people who pursue physician assisted death were "not acting out of a loss of respect for life, but they are acting out of a respect for what makes life worth living."⁶⁴ This group strongly associated dignity with respect for life and they respect quality of life over the quantity of it.

Compassion and Choices has an extensive web presence in addition to its hard copy publications and pieces in others' publications. This organization created understanding and pathos for death with dignity treatments and physician aided dying through personal testimonials on its website. Compassion and Choices used these testimonials and the wealth of clinical experience it accumulated over its existence to educate the public about DWD options and to

⁶² Coombs Lee, Barbara. "Life, Liberty, and The Right to Die: Column ." *USA Today*, 2 Apr. 2013, www.usatoday.com/story/opinion/2013/04/02/doctor-assisted-suicide-column/2043773/.

Page 2

⁶³ *Last rights*. Cantor, K., & Singing Wolf Documentaries. (2009).

⁶⁴ *Last rights*. Cantor, K., & Singing Wolf Documentaries. (2009). Barbara Coombs Lee interview

lobby for DWD acts across the US. As an example, one such testimonial comes from the case of Peggy Sutherland who died of terminal lung cancer in Oregon using the death with dignity act there and who was able to have all of her children and living siblings around her when she took her prescription and passed. Her pastor was also there, and after witnessing Peggy's death, is quoted in the testimonial saying, "The very essence of morality is rooted in the concept of autonomy."⁶⁵ These testimonials and documented experience are important tools in Compassion and Dying's arsenal for affecting broad and pervasive change in the field of death with dignity treatments.

One of the other ongoing stances of Compassion and Choices that affects the way death with dignity is viewed is that terminally ill patients are not committing suicide when they choose to end their lives. Coombs Lee emphasized in an interview and still emphasizes in other accounts that, "Suicide is an expression of despair and futility; Aid in dying is an affirmation of a person's dignity and rational self-determination."⁶⁶ This right again ties into the idea that a choice to die by a terminally ill person is a choice to respect the quality of life that that person has had and can no longer have in their current state. That quality of life will never return, and the person's suffering should not be held in higher esteem than their relief in terms of dignity and humanity. To make this concept of dignity even more specific, Coombs Lee explains that this organization "call[s] it aid in dying, our proponents call it suicide. [Terminally ill people] died of their disease but wanted to live."⁶⁷ These people would live if they had the choice. Coombs Lee compares terminally ill people who choose to end their lives to the victims in 911 who jumped from the burning World Trade Centers. To say they committed suicide would be a perverse insult to their humanity and to their circumstances. Those people did not want to die, but the alternative of doing nothing would have caused much more suffering than their choice to expedite death.⁶⁸ Compassion and Choices' candor about death with dignity treatments often hits emotional tones in the pursuit of

⁶⁵ "Last Rights", 2009. Kenneth Phiper, minute 22:40

⁶⁶ Coombs Lee, Barbara. "The Crime of Assisting a Suicide." *HuffPost*, 17 Nov. 2011.
https://www.huffpost.com/entry/the-crime-of-assisting-a_n_590847

Page 3

⁶⁷ Last Rights, 2009. Barbara Coombs Lee, minute 48:30

⁶⁸ Last Rights, 2009. Barbara Coombs Lee

persuading the public to listen and adopt the philosophies of a dignified end of life. This organization is committed to destigmatizing death with dignity and asserts that everyone who has had to bear watching other people die in long suffering ways understand that it becomes very clear what you don't want for yourself and for your loved ones when you're dying.⁶⁹ When we consider what we each will do at the end of life, it often becomes clear that there are no easy answers.⁷⁰ This organization does not have easy answers but they do have tangible answers.

Compassion and Choices' conceptualization of dignity and death with dignity care will be analyzed according to the three dimensions presented in the core research question: patient and doctor relationship, legal and policy factors, and medical technologies and protocols. This organization will be evaluated from its beginning in 2007 through 2011. This time span is pertinent because it marks the passing of the Palliative Care Act and the transition to present day DWD advocacy. The contemporary advocacy approach can be evaluated in a separate study and is being intentionally left out of this study. Compassion and Choices advocates for doctors to prioritize the patients' wishes and try to alleviate suffering at all costs. This organization does not support patients asking doctors to act illegally but it does still request that doctors inform their patients about all their care options even up to assisted death and that the doctor not abandon the patient in their suffering. For legal and policy factors, Compassion and Dying's leaders aided in authoring the Oregon Death with Dignity Act, and they strongly advocate that this is a successful piece of legislation and ought to be replicated in other states. They firmly believe that the only way to truly allow patients dignity at the end of life is to allow them to pursue all possible medical options within the realm of the law and out in the open with their loved ones and their community as they see fit. For medical technology and protocol, Compassion and Choices strongly utilizes palliative care and hospice care and has overseen several technological advancements in these areas to aid in patient suffering at the end of life. This organization advocates for patient control over pain medication and argues that full medication of pain symptoms is imperative to achieve dignity at the end of life, and that in the case that this does not

⁶⁹ Last Rights, 2009.

⁷⁰ Last Rights, 2009.

relieve suffering in hospice, that physician aided death may be the final resort in hospice. The sources that were analyzed in this chapter were selected because they articulate Compassion and Choices' teachings and methods of advocacy and they show the position that this organization held in society between 2007 and 2011.

Physician and Patient Relationship Factors:

Compassion and Choices' stance on how physician and patient relationships should exist in terminal illness is alluded to in the organization's name. Compassion for the patient and their suffering should be prioritized and the patient's suffering should be alleviated in every way possible. This means that physicians ought to communicate the full range of treatment options with their dying patients and should facilitate palliative care and hospice care for their patients when curative treatments are no longer effective. This transition from curative treatment into palliative treatment also requires a great deal of compassion and clinical honesty from a physician because it is not easy for caregivers to admit that the care is not going to save the life of their patient. Direct quotes and philosophies of Compassion and Choices will be analyzed in the remainder of this section to support the claims that this organization emphasizes that physicians and caregivers need to prioritize alleviating patient suffering and communicate all care options to patients who are dying.

Barbara Coombs Lee has experience working side by side with physicians as nurse and a physician's assistant, and she understands that "physicians have a lot of roles. One of them is to cure illness, another is to alleviate suffering and another is to never abandon the patient."⁷¹ This loosely refers to commonly cited argument that physicians who aid patients in dying are violating the clause of the Hippocratic Oath that swears physicians into doing no harm to their patients.⁷² Compassion and Choices would argue that only allowing a patient the choice to endure the suffering caused by their terminal illness is a form of harm, and furthermore it is harm at one of the utmost vulnerable times in life.

⁷¹ Last Rights, 2009. Barbara Coombs Lee, minute 14:29

⁷² Edelstein, Ludwig. *The Hippocratic Oath: Text, Translation and Interpretation*. Baltimore: The Johns Hopkins Press, 1943.

In 1989, the *New England Journal of Medicine* published a paper authored by American physicians who claimed that there is a moral imperative as a physician to compassionately help patients who cannot be relieved of their symptoms and pain at the end of life.⁷³ Compassion and Choices cited this study in its arguments and uses it to educate physicians and other caregivers in its advocacy outreach. It is the view of Compassion and Choices that alleviating suffering is a human duty that must be respected whenever possible.⁷⁴

To create more trust and cooperation between doctors and patients in death with dignity treatments, Compassion and Choices also changed the term physician assisted suicide to aid in dying or physician aided dying in all their communication and operations. Suicide as a term does not convey the meaning that this group teaches in death with dignity practices. In a *Huffington Post* interview in 2011, Barbara Coombs Lee informed the public that, “Doctors who acknowledge their patients' imminent death and accede to their thoughtful request are providing aid in dying, not assisted suicide.”⁷⁵ This is not the first time that she and her organization stressed that assisted suicide is not what is being discussed in death with dignity talks, but it is important that this claim was made on a socially public platform that reaches such diverse audiences as *HuffPost*. In the same interview, Coombs Lee goes on to say, “The contrast between aid in dying, in which a knowledgeable, merciful physician gives his elderly, dying patient the means to halt end -of- life suffering --- and assisted suicide, in which a malicious predator seeks out and victimizes physically healthy, mentally ill teens- could not be more clear.”⁷⁶ It is important that she specifically articulated the difference between aid in dying and aid in suicide because there was a distinct confusion between the two in the public sphere and this was only exaggerated by media coverage of school bullying and exploitation of mentally unhealthy vulnerable populations by perverse individuals at this time and in the past. Explicitly redefining this practice as aid in dying was a clear maneuver to distance the death with dignity movement from this type of media

⁷³ Final Rights, 2009.

⁷⁴ Final Rights, 2009.

⁷⁵ Coombs Lee , Barbara. “The Crime of Assisting a Suicide.” *HuffPost* , 17 Nov. 2011.
https://www.huffpost.com/entry/the-crime-of-assisting-a_n_590847

Page 2

⁷⁶ See Citation 69. Page 3

coverage and association to foster more trust in the movement and in the physicians who are the caretakers of terminally ill people.

Compassion and Choices also argues strongly that patients have a right to know what their full range of medical care options are in the case of terminal illness. Historically, doctors in the US in the early and mid 20th century were trained to withhold unsettling information from their patients about their prognoses. In an interview in 2008 with the *Los Angeles Times*, Coombs Lee argues,

“Not knowing what those [care] choices are [at end of life] makes it impossible for dying patients to choose them. It's a matter of simple decency and basic patients' rights. The basis of informed patient consent -- which is required for nearly all medical procedures -- puts the information and the power to choose in patients' hands. It shifts power from a condescending, top-down, 'doctor knows best' approach to a patient-doctor conversation. Ultimately, this will lead to patients' ability to work with their doctors to determine the best care option that fits with their values.”⁷⁷

Coombs Lee argues here and in all the advocacy work of Compassion and Choices that paternalism in medicine, or the phenomenon where doctors withhold information with the misguided intention of protecting the patient, must be eliminated in order to provide dignity and proper treatment at end of life in terminal illness. Without this shift in communication to provide more honest and collaborative medical care, “the information most patients receive before consenting to treatment as death nears remains woefully inadequate. Dying patients cannot wait forever for physicians to grant them the tools of informed decision making about disease-focused and palliative treatments at life's end.”⁷⁸ Open and honest communication about the full range of treatment options available to a patient is critical for physicians to grant their patients dignity at the end of life.

Legal and Policy Factors:

Compassion and Choices made enormous strides in legislation for death with dignity acts in multiple states and is partially responsible for the current state of legal death with dignity acts in the US. The leaders of Compassion and Choices outspokenly support having death with dignity

⁷⁷ Coombs Lee, Barbara. “End-of-Life Bill Empowers Sick Patients .” *Los Angeles Times* , 29 Oct. 2008, www.latimes.com/opinion/la-oev-lee29-2008oct29-story.html#.

Page 2

⁷⁸ Coombs Lee, Barbara. “The Palliative Care Information Act.” *New England Journal of Medicine*, vol. 365, no. 9, 2011, pp. 865–865., doi:10.1056/nejmc1107786.

practices including physician aided dying operate within the parameters of the law in lieu of illegally. Coombs Lee has stated that,

“Underground systems [of assisting death] are very dangerous to the threads of society. It encourages disrespect for rule of law and encourages disrespect for the medical profession, makes people hide, delays grief because it is hard to talk through grief and death when you can’t actually talk about the circumstances of it. There’s enormous harm that is being suffered everyday by patients, family, physicians, the rule of law in every state except for Oregon.”⁷⁹

It is a critical tenant of Compassion and Choices’ advocacy that legal physician aided death be lobbied for everywhere.

Before the Oregon Death with Dignity Act (ODDA) was passed in 1994, the Self Determination Act was passed in 1991 allowing patients to choose to decline lifesaving treatments. This position does not seem revolutionary but, at the time, it was. In regards to this early legislation affording patients autonomy and freedom of medical choice, Compassion and Choices argued that “bioethics in its early history did a great service by helping assure that people could have the right to say no to certain life-saving treatments.”⁸⁰ In the pursuit of writing the first death with dignity act in the US, Compassion and Choices founders had to maneuver around wording and scenarios that would cause harm to vulnerable populations who were not experiencing terminal illness. Compassion and Choices argued fervently during this time that “laws against assisted suicide are good laws that should stay on the books in every state where they appear.”⁸¹ Compassion and Choices asserted that the opinions of aid in dying critics are valuable to a point because terminally ill people are vulnerable, but that branding aid in dying as killing of vulnerable persons was incorrect because it discluded the information on how the ODDA works and discounted the protections in place to prevent abuse of the law. When legislatures tried to brand this movement as aiding suicide, Compassion and Choices had to circumnavigate the issue that “by the twentieth century, advances in psychiatry demonstrated that self-destructive thoughts called for mental health intervention, not criminal prosecution. So, legislatures transformed the crime of ‘suicide’ into the crime of ‘assisting a suicide’ to punish the aiding and

⁷⁹ Final Rights, 2009. Barbara Coombs Lee, minute 49:54

⁸⁰ Final RIghts, 2009. Minute 14:03

⁸¹ Coombs Lee , Barbara. “The Crime of Assisting a Suicide.” *HuffPost* , 17 Nov. 2011.
<https://www.huffpost.com/entry/the-crime-of-assisting-a n 590847>

abetting of harmful behavior of the mentally ill.”⁸² This is partially why the term physician-assisted suicide was rebranded as aid in dying. Compassion and Choices had to re-educate the public and the courts that when a person is terminally ill and experiencing unrelenting and terrible suffering, “the crime is assisted suicide. The kindness is aid in dying.”⁸³ Coombs Lee assured the public that, “When we drafted the Oregon Death with Dignity Act in 1994 we were careful to preserve and maintain the felony of assisting a suicide.”⁸⁴ In context of laws in the US that criminalize suicide as an act, Coombs Lee reminded the courts and the public that “those misguided laws hearkened back to feudal England, where citizens were deemed to ‘belong’ to the king, and killing oneself amounted to destruction of property obligated to the crown.”⁸⁵ In 20th century America, a patient belonged to himself and should not have the wills of others imposed upon him in his illness.

Compassion and Choices played a large role in the legalization of the ODDA and Coombs Lee served as one of the authors of the law. In her own words, Coombs Lee describes the ODDA as a “law [that] allows a terminally ill, mentally competent adult resident of the state to ask his or her doctor, ‘May I have a medication that I can take at a time of my own choosing if my suffering becomes unbearable?’ and the law allows the physician to comply with that request.”⁸⁶ This law does not mark the beginning of aid in dying in the United States, but rather marks the beginning of legal, medically sanctioned, regulated, and documented aid in dying in Oregon. The importance of the legalization can be seen in the meticulous documentation of testimonies of people who have used the law and testimonies of their loved ones and caregivers who report that it was critical for their sense of self and autonomy in an otherwise hopeless part of life. Compassion and Choices used these testimonies and the data maintained from the ODDA usage to teach the public and the medical system that,

“Thousands achieve comfort and peace of mind knowing they have choices. Fifteen years of experience since the Oregon aid- in -dying law took effect in 1998 reveals no

⁸² Coombs Lee, Barbara. “The Crime of Assisting a Suicide.” *HuffPost*, 17 Nov. 2011. Page 2

⁸³ See Citation 76. Page 4

⁸⁴ See Citation 76. Page 1

⁸⁵ See Citation 76. Page 2

⁸⁶ Final Rights, 2009. Barbara Coombs Lee, minute 24:19

evidence of abuse, coercion or negative impact on hospice care. Aid in dying is only for people dying of cancer, ALS or other fatal illness and is entirely voluntary for both patients and physicians.”⁸⁷

Just because the ODDA was legalized does not mean that it is an excessive preference among ill persons. Since 1991, about 1/10th of 1% of people who have died in Oregon have taken advantage of the death with dignity act.⁸⁸ This is a very small population of people who have obtained the medication to end life under Oregon law and used it for its purpose. Having the choice available to end life was often more valuable to patients than actually utilizing the law. It was valuable for people to know that if they were still alive and suffering with their terminal illness, it was because they chose to be and not because it was the only option they had. Terminal illness is a terrible phenomenon to witness and to endure and hospice and the Oregon Death with Dignity Act only seek to lessen the maladies of this phenomenon and bring people back to their identities and sense of self and ultimately to find relief and dignity.

When the Palliative Care Information Act of 2011 was passed, Compassion and Choices used this legislation to advocate that patients have more communication with their doctors about alternative end of life care. This act further facilitated Compassion and Choices ideology that terminally ill people deserve access to the full spectrum of treatments possible because it mandated that doctors communicate that spectrum to their terminally ill patients. This obligatory conversation between patient and physician about terminal illness treatments is an important part of Compassion and Choices’ conceptualizations of death with dignity. A patient trusts their doctor and relies on them especially in this vulnerable period of life and it is more dignified for the patient to receive information about end of life options from the doctor that they trust rather than from an

⁸⁷ Coombs Lee , Barbara. “Life, Liberty, and The Right to Die: Column .” *USA Today* , 2 Apr. 2013, www.usatoday.com/story/opinion/2013/04/02/doctor-assisted-suicide-column/2043773/.

Page 2

⁸⁸ Final Rights, 2009.

outside source. The Palliative Care Information Act initiated a period of DWD advocacy in which palliation and hospice were openly discussed openly as mandated by the law.⁸⁹

Compassion and Choices continues to this day to advocate for death with dignity acts in states where it is not yet legal and they prefer to direct patients who want to pursue physician aided dying to states where there are death with dignity acts in place rather than facilitate patients pursuing this practice outside of the law.

Medical Technology and Protocol Factors:

Compassion and Choices relies heavily on hospice and palliative care to support the needs of the individuals who seek out their advocacy. Luckily, at this stage in history, hospice is a highly developed philosophy and set of treatments that is fairly attainable for patients financially and logistically. In the past, organizational histories of hospice has been less attainable for various reasons. In a testimonial from a patient published on their site, Compassion and Choices addresses the issue with terminally ill patients that “as soon as one disability is focused on and adjusted to, another disability would come along.”⁹⁰ It is very difficult to treat a patient whose body is systematically becoming debilitated. This is why hospice is a valuable resource for terminally ill people. Hospice creates a care plan that prepares caregivers, loved ones, and patients for the projected deterioration of the body and reacts with the provided care plan as soon as those separate deteriorations occur. Outside of hospice, patients may suffer with these different disabilities longer before medical reaction occurs, because curative and hospital treatments do not target care to provide comfort for the patient and support them through accessory symptoms to terminal illness in the way that hospice and palliative care do.

This support and comfort care is part of why hospice is so attractive a medical protocol in the case of terminal illness. In hospice, a patient is removed from hospital and other clinical

⁸⁹ Coombs Lee, Barbara. “The Palliative Care Information Act.” *New England Journal of Medicine*, vol. 365, no. 9, 2011, pp. 865–865., doi:10.1056/nejmc1107786.

⁹⁰ Final Rights, 2009.

medical settings and they are placed in their home or another place of comfort and familiarity. Their care is brought to them and administered by a hospice nurse or their loved ones. The intention of care is to provide comfort to the patient and to manage the impacts of their symptoms rather than to cure them or fix the symptoms. Compassion and Choices believes that “hospice is a major player in allowing people to spend their end in a place that is familiar and comfortable to them”⁹¹ Because hospice brings a person back to a place that is their own and prioritizes suffering relief, hospice really facilitates dignity and autonomy at the end of life. “Hospice has been a great empowerment generator. It is a philosophy and not a place. Nothing is done to hasten death and nothing is done to prolong dying”⁹² Hospice care gave much more pain control and opportunity for patients’ choices in end of life care and treatment. The changes that hospice brought to dying person’s quality of life at end of life were valuable.

Pain management is one of the largest treatments and priorities that makes hospice care so effective at relief and aid. Terminal illness can destroy a person’s quality of life in a myriad of ways, but constant and unignorable pain is one of the most dehumanizing parts of this. The degree of pain that these people experience can bend the psyche, harm spiritual and emotional identities, and render daily existence miserable and undesirable. Modern medicine has remarkable tools to manage pain levels and to even neutralize the phenomenon all together in some circumstances.

The tools and strong pain medications of the medical system cannot be used without tradeoffs. The medications used to manage intense pain can be addictive and can also hinder lucidity. Many caregivers and social influencers expressed concern in this era that it was irresponsible of hospice and caregivers to medicate terminally ill patients so heavily for pain control because they were at risk for opiate addiction and a hastened death due to the morbidity of the pain meds. The notion that overmedicating terminally ill people in hospice for pain was

⁹¹ Final Rights, 2009. Barbara Coombs Lee, minute 14:40

⁹² Final Rights, 2009. Minute 19:05

ludicrous to Compassion and Choices and is still a ridiculous notion in the advocacy community today. In the case of terminally ill people, “the proper dose of medicine for pain is any dose that relieves the symptoms.”⁹³ Causing theoretical harm to a dying patient by over medicating them and simultaneously giving them some comfort and relief is a double effect as described by Compassion and Choices. The double effect is that proper pain medication for terminally ill people may hasten death (a harm) and that it relieves terrible suffering for the patient. Compassion and Choices argued that this double effect was permissible and even encouraged both ethically and legally for terminal illness.⁹⁴

According to Coombs Lee, there is an ideal in hospice care, and it entails maximum relief for the patient and a full exhaustion of medical, spiritual, and social resources to give that relief to the patient. In hospice that was correctly managed in the views of Compassion and Choices, “pain was continuously managed and with pain control, old personalities were restored. Persons can sleep, eat, interact. In fact, some people lived longer simply because they were comfortable.”⁹⁵ Proper control of pain was a crucial factor in giving a person the dignity and quality of life in terminal illness that made them comfortable with continuing to live even with great suffering. Inadequate pain management could make people lose their desire to live and could even expedite their death. For some people, hospice and palliative care are enough to satisfy end of life wishes and needs. For some, terminal illness is still too unbearable for personal reasons and the only way to achieve relief and dignity is to utilize choice and autonomy in elective death as the last frontier for relief and empowerment in terminal illness.⁹⁶

Compassion and Choices states that most people are mystified about how hospice works and what role it plays in terminal illness treatment in this period. Yes, it is available and even highly accessible, but it is still misunderstood. Much of the public seemed to think of people

⁹³ Final Rights, 2009. Sydney Wazner MD, minute 18:05

⁹⁴ Final Rights, 2009.

⁹⁵ Final Rights, 2009. Barbara Coombs Lee, minute 16:46

⁹⁶ Final Rights, 2009.

entering hospice as giving up on curative care rather than as giving themselves relief from useless and aggressive curative treatments in an attempt to restore quality of life at end of life. Those who do go into hospice are ending curative care, but this is because curative care is no longer curing the patient's disease. They also seemed to think that hospice was a prolonged process whereas most people do not enter to hospice until they are truly at the end of life and it ends up lasting approximately a week. The same goes for people pursuing assisted dying.⁹⁷ Part of this confusion about end of life treatment realities and perceptions comes from the communication of the medical community to the public. "A study published [in the 90's] in the *Journal of the American Medical Association* revealed that communication between doctors and patients was crucial in ensuring that people received the best treatment at the end of their lives. Researchers found that many dying patients underwent rigorous cancer treatments just days before their deaths -- not realizing how close they were to the end. The study revealed that many doctors either failed to tell their patients how little time they had left to live or grossly overestimated a patient's remaining time by as much as 350%."⁹⁸

Barbara Coombs Lee claimed after the Oregon Death with Dignity Act was passed "people deserve both palliative care with hospice care and the option of aid in dying and in Oregon now, they get both."⁹⁹ These two treatments do not make sense without the other and cannot be considered separately. By this, she means that palliative care and hospice care must be fully attempted and exhausted before a patient decides that there are no other options but physician aided death. Physician aided dying is not a first, early, or preferred option in terminal illness. It is the final resort that people pursue when all other treatments and regimens have failed them and their suffering is too great to bear. Physician aided dying ought to occur in hospice and is not a separate treatment that undermines or negotiates against hospice philosophy.

⁹⁷ Final Rights, 2009.

⁹⁸ Coombs Lee, Barbara. "End-of-Life Bill Empowers Sick Patients ." *Los Angeles Times* , 29 Oct. 2008, www.latimes.com/opinion/la-oeew-lee29-2008oct29-story.html#.

Page 1

⁹⁹ Final Rights, 2009. Barbara Coombs Lee

Compassion and Choices utilized their database of patient testimonies to communicate the marriage between hospice and physician assisted suicide in the following example. Peggy Sutherland, mentioned earlier, died of terminal lung cancer. When she used the ODDA to end her suffering, she testified that even after the 15-day waiting period to reapply for the treatment, she didn't waiver. She had done all the living she could do and no longer felt like she could do the things that made her feel like she was living. She received her medication and had a ceremony to end her life peacefully surrounded by her children and friends. Ceremonies of this nature around death were common with the ODDA and gave people the opportunity to pass under their own terms.¹⁰⁰ The ceremonies and dying processes selected by patients are not medical protocol, but they are still protocol that terminal patients enacted that conceptualized their dignity and hospice facilitated them.

Conclusion:

Compassion and Choices established a legacy of care and legal advocacy in its early years, but it is still an important organization today. The early conceptualizations of dignity that came from this organization are still pervasive now and have seriously impacted the people and professional fields around death with dignity. Compassion and Choices was partly responsible for drafting the Oregon Death with Dignity Act and they are also credited with raising funds and seeding a grass roots following and support for this legislation. This support spread by their hand to Washington and then subsequently Vermont to pass death with dignity acts. Compassion and Choices does not advocate for terminally ill persons to work outside of the law to seek care and aided dying because they have witnessed the damage that can cause and believe it undermines the medical system's legitimacy and causes more harm than good for the people involved.

The commitment to working within the law does not mean that Compassion and Choices deterred people with terminal illness from seeking out assisted dying if that's what they need to

¹⁰⁰ Final Rights, 2009.

achieve peace and their version of dignity. It means that the advocacy group encouraged people to go seek care in places where assisted dying is legal and to seek legalization of aid in dying in the areas that they are in. Compassion and Choices has recognized that this is a lofty expectation of people who are disabled by their illness and already have limited health and mobility. These limitations are why the organization pushed so hard and continues to advocate relentlessly to legalize physician aided dying in all US states.

Compassion and Choices is well known for advocating for people to have the right and option to pursue physician aided dying in terminal illness but this is not the first treatment that they recommend to dying people. This group advocated strongly for people to consider palliative care and hospice care when curative treatments no longer worked and when the morbidities of curative treatments caused more suffering than benefit. Compassion and Choices widely disseminated information on what hospice care was and how to engage in it. This was important for giving terminally ill people comfort care that made life more livable and reduced the incidence of people wanting to hasten death.

Beyond advocating generally for hospice care, Compassion and Choices also advocated for adequate control of pain in hospice care. There was interesting and problematic concern at this time that there would be dependency on pain medication among terminally ill patients and that using too much pain medication on them would be detrimental to their health. Compassion and Choices educated the medical community and public through their work that this is a moot problem because terminally ill people are not worried about their health so much as they are worried about their comfort and quality of life in the short span of life that remains. Pain should be managed to the degree that it does not exist anymore and, as long as patients are aware that this treatment regimen may hasten death and consent to those terms, it is allowable. Dependency is not an issue here because patients will not have a life after the treatment to worry about addiction and, because the patient is not seeking the drug itself so much as they are seeking the very tangible relief that the drug brings.

Compassion and Choices continues to advocate for the rights of patients and the protection of patients and doctors in death with dignity practices. It is the largest and most active death with dignity advocacy group in the US and has been for years. The clinical experience and awareness of this group is unparalleled and the definitions of dignity that they have conceptualized for end of life phases are highly valuable in medicine, law, social awareness, and spirituality of patients. Dignity is typically associated with patient empowerment and patient choice but Compassion and Choices has explored what this broad concept means and built more extensive platforms and pathways by which patients can achieve autonomy and empowerment. They have had an enormous impact on the death with dignity movement in this country and will likely continue to impact this movement and the vulnerable persons who belong to it well into the future.

Conclusions:

This study of 1985 to 2011 revealed some clear changes in death with dignity conceptualizations as evidenced by changes in patient doctor relationships, medical policy and law, and medical technologies and protocols around terminal illness. The three organizations analyzed in this study are the three-main death with dignity advocacy groups in the United States chronological in order, the groups are the Hemlock Society, Compassion in Dying, and Compassion and Choices.

The initial teaching of the Hemlock Society revealed in their publications was that people who are suffering with terminal illness deserve the right to end their life on their own terms whether or not their caregivers approve or help facilitate that death and whether or not the law approves that death. This was a period in which many legal battles sprouted over terminally ill patients dying at home via aid from their doctor or loved ones. These deaths were not legal and were often disruptive to the loved ones and caregivers of the ill patients. At this time, the Hemlock Society articulated that self-determination at the end of life was a human right and needed to be respected, but there were limited options on how to systematically facilitate self-determination and human dignity at end of life. The Hemlock Society's mission statement said that they urged people to use the help of their physicians when possible for self-determination, but their writings tended to also suggest that people bypass the help of the physician if it seemed the physician would disapprove of their goals at the end of life and refuse to cooperate.

In the middle period of the Hemlock Society, *Final Exit* was published and changed the tone of the organization. *Final Exit* prescribed very specific ways for a person to end their life at home with either household items or a medical prescription. These methods all sought to enable peaceful and nonviolent deaths and the book claimed to only be intended for terminally ill people. There were many critics of this era of Hemlock Society's advocacy because this book informed people that in terminal illness, assisted dying, or at this time "self-deliverance," was the main way

of achieving death with dignity and it also blatantly encouraged self-deliverance outside of the law and the medical system. Furthermore, the Hemlock Society published this book and other items that instructed individuals on how to die and how to act in terminal illness, but the society refused to consult patients directly. Critics thought the group was irresponsible and even cruel to teach vulnerable people such extreme measures but not be present with those people as they undertook those measures. This position was controversial and even inflammatory, but it is important to understand that the Hemlock Society believed this was facilitating dignified deaths and this is how they conceptualized death with dignity in the early 90's.

In the late stage of the Hemlock Society, the advocacy group stood by its instructions in *Final Exit* and still believed that people have the right to choose how to die in the case of terminal illness and suffering. However, the society began to concede that more effort needed to be made to legalize self-deliverance or, now, physician-aided death. Their writings shifted to acknowledge that having patients work outside of the law to die could be harmful to their families and to the DWD movement. The conceptualizations of dignity at the end of the Hemlock Society were that physicians ought to put patients' wishes before their own qualms and aid in dying, that aided dying is the most discussed protocol to achieve DWD in the group, and that the American legal system ought to begin accommodating self-deliverance for patients.

Compassion in Dying was the second advocacy organization in this study. This group can be characterized by its hands-on advocacy with people, legislative efforts in the Oregon Death with Dignity Act, and insistence that patients utilize hospice and palliative care before considering physician-assisted death.

For the hands-on advocacy component, Compassion in Dying structured their organization in a hierarchical system where advocates consulted directly with patients and even with the care teams and social circles of the patients if the patient so chose. This direct contact facilitated more in-depth conversations about alternative options to curative treatment in terminal

illness and expanded patients' opportunities for death with dignity practices at the end of life. The organization believed that terminally ill people should not pursue end of life treatments outside of the medical system, meaning that they should not take their own life in the ways prescribed by the Hemlock Society. Compassion in Dying said that a patient should not consider assisted suicide until their suffering was not relievable in hospice and palliative care and then the assisted death should be mediated by the patient's doctor.

Compassion in Dying recognized that it was only fair to ask patients to work within the medical system for inaccessible treatments if the advocacy group worked to make those treatments legally accessible. Compassion in Dying spent a lot of energy and resources on lobbying for the Oregon Death with Dignity Act and Barbara Coombs Lee, one of the founders, lent her career experience and advocacy experience to the writing of the act to maximize benefit and protections for patients and the medical providers who help them. This marked a change in the role of advocacy groups in the US from helping patients legally and not just with social and medical advice. Compassion in Dying supported legislation in other states but was only successful in Oregon.

Compassion in Dying conceptualized dignity at the end of life as an experience where all medical options were utilized to ease a person's pain and suffering and to make them feel comfortable and still in touch with their personal identity. If the wide range of treatments and philosophies meant to achieve that relief did not work, then Compassion in Dying facilitated physician assisted death but only within the realm of the medical system and preferably only in the realm of the law once it became legal in Oregon. In all cases though, this advocacy group called for open communication between patients and doctors about the full spectrum of care options and encouraged patients to use their doctors to achieve those care options and to not rely on external forces alone.

Compassion and Choices is the final Advocacy Group analyzed in this study. This group is characterized by its expansive modern presence in the death with dignity sphere and by its policy lobbying across the US that has successfully contributed to passages of death with dignity acts in several states. Barbara Coombs Lee, the director of Compassion and Choices and former leader of Compassion in Dying, has stated that it is a detriment to the fabric of society for people to take their life in terminal illness outside of the bounds of the law and the infrastructure of the medical system.¹⁰¹ Compassion and Choices does not agree with undermining physicians and the law in this manner and does not advise people to do this.

Compassion and Choices is very similar to Compassion in Dying in the remainder of their advocacy work, in part because Compassion and Choices grew out of Compassion in Dying. One of the more unique medical technology and protocol issues that Compassion and Choices advocated for to facilitate dignity was the allowance of patients to use maximum doses of morphine for pain management. They criticized the concern in the medical system that terminally ill people would become addicted to pain medications and experience adverse effects from pain medication usage such as losing lucidity and even hastening death. Compassion and Choices promoted the view within the medical system and among their patients that these issues should not be of concern because the terminally ill will not experience the burdens of addiction on active life and that they deserved the full amount of relief from their symptoms possible. Relief made life more bearable and even made some patients enjoy their lives longer without adequate pain management.

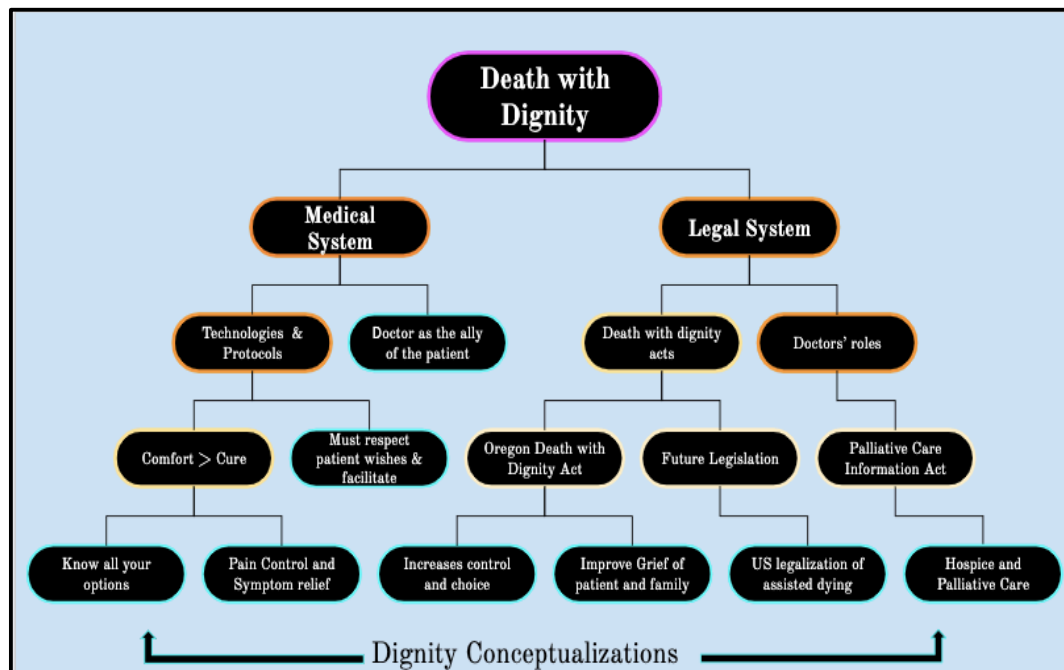
One of the main conceptualizations of dignity that can be attributed to Compassion and Choices is the concept that having choices in treatment options gives dignity to patients and offers them humane solutions to feel empowered and more peaceful at the end of life. Compassion and Choices also thought that giving patients a wider range of choices even gave them enough relief to where they lived longer lives. The final piece of legislation that was studied

¹⁰¹ Last Rights, 2009.

in this research is the Palliative Care Information Act of 2011. This act further facilitated Compassion and Choices ideology that terminally ill people deserve access to the full spectrum of treatments possible because it mandated that doctors communicate that spectrum to their terminally ill patients. This obligatory conversation between patient and physician about terminal illness treatments is another facet of Compassion and Choices' conceptualizations of death with dignity. A patient trusts their doctor and relies on them especially in this vulnerable period of life and it is more dignified for the patient to receive information about end of life options from the doctor that they trust rather than from an outside source.

The following chart (Figure 1) shows the framework of how conceptualizations of death with dignity were crafted in this thesis from the three-main variable examined of patient and doctor relationship, legal and policy factors, and medical technologies and protocols in the literature of the advocacy groups examined. The teal ovals in this chart are the conclusive conceptualizations of death with dignity and how to implement it in for terminally ill people in society. The orange boxes are the different facets of the three variables listed above that all of the literature was examined with respect to. This chart shows a large range of conclusions for how to define and facilitate death with dignity and this is intentional. The conceptualizations of death with dignity need to span across legal areas, medical influence, and social levels because terminal illness and the dying processes associated are not an isolated issue to any one field and they do not affect any one demographic. This is a broad issue that permeates so many areas of society and affect everyone who does not die in a sudden accident. The teal conclusions in this chart serve not only as conceptualizations for how we can think of and understand a dignified death, but they also serve as tools for how to enable people to pursue their own versions of dignified death.

Figure 1: Death with Dignity Conceptualization Conclusions



Death with Dignity treatments and laws have changed over the last few decades to transform the experience of a dying patient from first being alone and with inadequate support to a period of having options outside of hospital care that are not legal and medically supported but still give a patient their choice, to now having well rounded supportive care that works to give a person all the relief possible and medically/legally facilitated options to end life when relief is no longer possible in the support infrastructure of hospice and palliation. This large transition was made possible by the testimonies of people who died at different stages of this movement evolution, of the advocacy workers who lobbied for policy change and educated doctors on support treatments, and by the expansion of hospice programs in America. It's an important transition, because terminal illness is not lessening in the United States, but the suffering around it can now be lessened much more in social, physical, spiritual, legal, and personal ways.

Dignity is still a difficult phenomenon to universally conceptualize because it is a personal concept to each person beholding their own dignity, but this study analyzed the evolution of the

modern idea of a death with dignity processes where a person is given choices about their medical care, about where they live and receive care at the end of life, where their pain can be properly managed, and where they are able to legally access physician assisted suicide if that becomes the only recourse for relief. Future studies on death with dignity have a lot of potential to expand upon this definition and give it more dimensionality by interviewing people who have terminal illness on what they believe would give them dignity in their phase of life. Another way to expand upon the conceptualizations of dignity produced in this study would be to expand the foundations of the research to include information on hospital policy, throughout the periods caused in this study on how patients who were terminal were handled once they enter the hospital system. This expansion would focus on whether patients were treated for their short-term symptoms or if they were treated to cure the disease and what type of conversations about withdrawal of care and morbidities of curative treatment were facilitated among those patients and care providers. It would also be valuable to investigate in future studies how the views of different types of care providers differ on how to treat patients who are terminally ill and how to communicate with them. Some different care providers that ought to be investigated in that study are family doctor vs oncologist, ICU doctor vs palliative care doctor, nurse vs physician, etc.

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APPENDIX

COMPREHENSIVE ORGANIZATIONAL BIBLIOGRAPHY OF ADVOCACY GROUPS IN STUDY

CONCLUSION CHART: FIGURE ONE

APPENDIX A

COMPREHENSIVE ORGANIZATIONAL BIBLIOGRAPHY OF ADVOCACY GROUPS IN STUDY

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APPENDIX B

CONCLUSION CHART: FIGURE ONE

